Barriers and Facilitators to Colposcopy Attendance Following an Abnormal Pap Smear: Patient and Provider Perspectives

By

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DECLARATION

I, Shanaaz Dawood, hereby declare that the work on which this dissertation/thesis, is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to submitted to another degree in this way or any other university.

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Thesis Abstract

Cervical cancer is a public health problem particularly in developing countries where incidence of cervical cancer remains high, either due to a lack of screening or poorly organised screening programmes. Cytology based cervical screening is only beneficial if women with abnormal Papanicolaou (Pap) smears are appropriately investigated. Colposcopy attendance following an abnormal Pap smear is a major problem in South Africa. The aim of this study was to explore barriers and facilitators to colposcopy attendance following an abnormal Pap smear result.

A qualitative study was conducted at a public sector tertiary hospital colposcopy service and two primary health care clinics in Cape Town, South Africa. Data collection included 32 semi-structured interviews: 12 face-to-face interviews with colposcopy clinic attendees, 12 telephonic interviews with colposcopy clinic non-attendees and 8 face-to-face interviews with health care providers. Client interviews explored barriers and facilitators to colposcopy attendance; knowledge and experiences of Pap smears, cervical cancer and the colposcopy procedure; scheduling of colposcopy appointments; provider communication; reasons for non-attendance; and community support and beliefs. Provider interviews explored barriers and facilitators to colposcopy attendance from a provider's perspective, the colposcopy referral process, and provider challenges in the provision of Pap smear or colposcopy services.

Results from this study highlighted that the main barriers to colposcopy attendance were: poor levels of knowledge of the importance of a Pap smear and the colposcopy procedure; a lack of awareness of cervical cancer as a disease; a fear of cancer; the asymptomatic nature of the disease; and transport costs. Health system factors that impacted negatively on colposcopy clinic attendance included: the inadequate feedback of Pap smear results – clients were not informed of Pap smear results or colposcopy appointments and therefore did not attend; a disjointed system of colposcopy scheduling; and staff shortages which resulted in less time for client tracking. Factors which promoted colposcopy attendance included experiencing symptoms; a family history of cancer due to the experience

with death; colposcopy services situated closer to clients; and social support received from family members.

Addressing these barriers requires promoting client knowledge with educational materials and improving provider communication with clients. In addition, establishing colposcopy services closer to clients and standardising the system of colposcopy scheduling can improve colposcopy adherence.

This thesis is presented in 3 parts

Part A: The proposal for a qualitative study exploring barriers and facilitators to colposcopy attendance following an abnormal Pap smear result. The proposal was submitted to the University of Cape Town Health Sciences Human Research Ethics Committee for ethics approval.

Part B: Includes a review of the literature evaluating cervical screening programmes, and barriers and facilitators to colposcopy attendance, in developed and developing countries. Gaps in the literature include qualitative research exploring reasons for poor colposcopy attendance in South Africa. Little is also known about women's knowledge and experiences of an abnormal Pap smear result, cervical cancer and the colposcopy procedure in a South African setting.

Part C – Includes a journal article, prepared to meet requirements of the BMC Public Health journal. The article reports on barriers and facilitators to colposcopy attendance following an abnormal Pap smear result from client and provider perspectives.

Referencing Style: The BMC Public Health referencing style has been used throughout the dissertation (Appendix 11)

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List of Abbreviations

AIDS - acquired immune deficiency syndrome

AGUS - atypical glandular cells of undetermined significance

ASC-H - atypical squamous cells, cannot exclude high grade squamous intraepithelial lesions

ASCUS - atypical squamous cells of undetermined significance

ASIL - atypical squamous intraepithelial lesions

ASIR - age standardised incidence rate

ASMR - age standardised mortality rate

CHIP - Cervical Health Implementation Project

CHW - community health worker

GSH - Groote Schuur Hospital

HIV - human immunodeficiency virus

HPV - human papillomavirus

HSIL - high grade squamous intraepithelial lesions

LSIL - low grade squamous intraepithelial lesions

LTFU - loss to follow-up

Pap - Papanicolaou

SES - socioeconomic status

STI - sexually transmitted infection

UK - United Kingdom

US - United States

VIA - visual inspection with acetic acid

PART A: PROJECT PROPOSAL

PART A: PROJECT PROPOSAL

Barriers and Facilitators to Colposcopy Attendance Following an Abnormal Pap Smear Result: Patient and Provider Perspectives

1. Introduction

Cervical cancer is a major public health concern affecting women worldwide. It is the second most common cancer among women globally [1]. In 2012, worldwide estimates were 527 624 new cervical cancer cases and 265 653 deaths [2]. More than 85% of cases occurred in developing countries [3]. A decline in cervical cancer incidence and mortality has been achieved in developed countries, due to the successful implementation of organised cytology-based screening programmes [4], with high screening coverage and treatment of precancerous lesions [5]. In contrast, developing countries either have no or poorly organised screening programmes [6] with poor follow-up and feedback mechanisms, inadequate referral systems and under-treatment of abnormal Papanicolaou (Pap) smears [7].

A successful cytology-based screening programme is dependent on women with abnormal Pap smears attending follow-up assessments [8]. Abnormal smears are classified by the Bethesda system as: a smear having atypical squamous cells of undetermined significance (ASCUS); high grade squamous intraepithelial lesions (HSIL); low grade squamous intraepithelial lesions (LSIL) or atypical squamous cells, but cannot exclude HSIL (ASC-H) [9]. The ultimate goal of cervical screening, which is the prevention of cervical cancer, is only beneficial if women with abnormal smears are appropriately investigated and treated [10]. If women with abnormal Pap smears do not attend follow-up sessions, this will result in a decrease in screening effectiveness, reduce the efficiency of health care resources, and increase programme costs [11].

In South Africa, cervical cancer is the second most frequent cancer among women [1]. It is estimated that 5743 new cases and 3027 deaths occurred in 2008, with an age standardised incidence rate (ASIR) of 26.6 per 100 000 women [12]. Incidence and mortality from cervical cancer is projected to increase in South

Africa by more than 21% and 27% respectively by 2025 if current trends continue [1].

A National Cervical Cancer Screening Policy was introduced in South Africa in 2000, stating that women between the ages of 30- 60 years are entitled to three free Pap smears in their lifetime ten years apart [13]. The objective of the policy is to decrease the number of new cases of cervical cancer by identifying and treating early stages of the disease [13]. If well implemented, the policy has the potential to reduce cervical cancer incident cases by 67% over a ten year period, assuming that a high coverage is attained [14].

Once women have been screened with the Pap smear test those with HSIL, persistent LSIL or ASCUS are referred for colposcopy [15]. Colposcopy is a specialised procedure using a colposcope with a strong light to examine the uterine cervix for cervical abnormalities and allows a biopsy to be obtained for a histological diagnosis [16]. Colposcopy services in South Africa are primarily offered in urban areas, at tertiary and a few secondary hospitals, and performed by a gynaecologist [17].

South Africa faces many challenges in the implementation of an effective cytology-based screening programme [7]. Some of these challenges include: human resource shortages, resource constraints, poorly functioning health systems [18], competing health priorities, and lack of access to health services, particularly by women with a low socioeconomic status (SES) living in rural or urban areas [5]. A key challenge is poor colposcopy attendance following an abnormal Pap smear [7].

Loss to follow-up (LTFU), non-adherence, and default to follow-up care have been used interchangeably in the literature. Non-adherence has generally been classified as failure to present at a follow-up assessment or treatment following an abnormal Pap smear result within a specified time frame [19, 20]. Time frames vary between studies. The National Breast and Cervical Cancer Early Detection Programme in the United States (US) has defined adherence as completion of diagnostic tests within 60 days of the abnormal Pap smear result [21], whereas in a systematic review from the US, the reviewed research defined follow-up care

ranging from four to six weeks to within 18 months or by the number of follow-up appointments attended [19].

A study in Gauteng reported LTFU of over 50% among women who were referred to colposcopy with high grade lesions and invasive cancer [22]. Health system related reasons for LTFU were poor record keeping and appointment scheduling procedures, inadequate capacity at the colposcopy services and a lack of client tracking systems [22]. Client reasons for non-attendance were, however, not explored. Similar findings were noted in another South African study conducted in the Western Cape where a 33% LTFU in colposcopy attendance was recorded in 2009 [23]. Patient reasons for non-attendance in this study were not investigated.

The literature identifies many factors which contribute to LTFU following an abnormal Pap smear. The majority of these studies have, however, been conducted in developed country settings. These factors have broadly been classified into individual, health system, psychosocial and community factors [19, 24]. Individual factors include socio-demographic and patient level factors [19, 24]. Psychosocial factors include clients' feelings and experiences [19, 25]. Health system factors include provider communication, administration procedures and client tracing [26]. Community factors include population characteristics, and cultural values and beliefs [24, 27].

Either being very young (<30 years) or older (>55 years) has been shown to negatively impact follow-up care (colposcopy or treatment) of an abnormal Pap smear [24, 28]. Being very young was associated with a lack of knowledge or understanding of cervical cancer as well as being less exposed to gynaecological interventions compared to older women [8]. Lesion severity has also been shown to influence colposcopy attendance [19]. Women with more severe lesions (HSIL) were more likely to attend a colposcopy follow-up to women with lower grade lesions [29].

A study conducted in the US showed that lower levels of education, being unemployed or having a low income negatively influenced colposcopy attendance [30]. In contrast, other studies have shown no association between age, level of education and colposcopy attendance [21, 31]. In studies from the US,

personal factors that influenced colposcopy attendance included concerns about fertility, family responsibility, disruption of work, and transport difficulties [24, 26].

The most common psychosocial factors identified in studies involving barriers to colposcopy were fear and anxiety [24, 26]. This includes: anxiety and fear with regard to the procedure, fear of the unknown or what the diagnosis may be, fear of having cancer, not understanding the meaning of the smear result or meaning of the test, fear of death, and fear of not being able to take care of oneself or family due to ill health [19, 25, 32]. In a US study, Schoenberg et al [24] reported that a fear of cancer along with having knowledge of the importance of follow-up care facilitated a group of women to attend their follow-up appointment (repeat Pap smear, colposcopy or treatment), whereas, it deterred others from seeking follow-up care. In a South African study, Moosa et al [33] showed that 50% of women presenting at a colposcopy clinic had elevated anxiety scores, however, reasons for the anxiety were not explored. Limited South African data on the psychosocial factors influencing colposcopy attendance are available.

In studies from the US and the United Kingdom, health system factors reported to influence follow-up care included: long waiting times for a colposcopy appointment; the gender of the colposcopist [34]; and poor provider communication with regard to the procedure, explanation of the results and the diagnosis [19, 26]. Women attending colposcopy appointments reported that time spent with a provider before the procedure; being given explanations about the procedure and the results, and being provided with choices during the consultation offered reassurance and decreased anxiety, as well as contributed to positive experiences relating to colposcopy [25]. In South African studies, health system barriers reported to influence colposcopy attendance include Pap smear results not being communicated to patients, inadequate record keeping, and failure to book colposcopy appointments [22, 23]. Factors giving rise to these administrative failures in South Africa need to be further explored.

Community factors also impact on adherence. These factors include patient concern regarding confidentiality among close knit communities, particularly in rural areas; lack of community awareness about seeking follow-up care, and

cultural beliefs [24]. Information on community factors influencing colposcopy attendance in South Africa is not available.

2. Justification:

Colposcopy adherence is a major problem in developing countries. The literature has identified many factors contributing to colposcopy non-attendance. However, the majority of these studies are quantitative and were conducted in developed countries. The different country contexts and health systems mean that the results from these studies might not be applicable to South Africa. Qualitative studies exploring reasons why women in South Africa fail to attend their colposcopy appointment following an abnormal Pap smear result, and the knowledge and experiences of women attending colposcopy clinics in South Africa are limited. This study seeks to understand the reasons that influence women in attending their colposcopy appointments, both from client and provider perspectives. A better understanding of these factors could enable health authorities to direct interventions towards these barriers and improve colposcopy attendance.

3. Aim of the Study:

To explore barriers and facilitators to attending colposcopy assessment following an abnormal Pap smear result among women in Cape Town, South Africa.

3.1 Objectives:

1. To develop an understanding of why women fail to attend colposcopy assessment following an abnormal Pap smear result.

2. To explore knowledge and experiences of women with an abnormal Pap smear result referred to colposcopy assessment.

3. To explore barriers and facilitators to colposcopy attendance by women following an abnormal Pap smear result from a health provider perspective.

4. Methodology

4.1 Study design:

This will be a qualitative exploratory study informed by McLeroy's ecological model [35]. McLeroy's ecological model is a variation of Bonfrenbrenner's ecological model of 1979. It provides a framework for understanding health behaviour and is based on multiple interacting levels of influence [36]. The model views behaviour as affected by and affecting the social environment. The ecological model looks at the interrelationship between five levels [35]:

1. Intrapersonal or individual level: includes characteristics of the individual, such as skills, knowledge, experiences, or anything occurring within the self or the mind.

2. Interpersonal level: includes formal and informal social networks and social support systems, for example friends, family and workgroups.

3. Institutional or organisational level: is concerned with how organisational groups can influence behaviour change. It includes: social institutions, with organisational characteristics; formal and (informal) rules for operation and regulation; for example work organisations.

4. Community level: includes relationships between organisational institutions and informal networks within defined boundaries, for example church groups and voluntary associations which influence the larger community values, beliefs and norms.

5. Policy level: includes local, state and national policy and laws.

The ecological model together with the literature will be used as a framework to better understand the reasons why women fail to attend their colposcopy appointments and to determine the knowledge and experiences of women referred to colposcopy. The model will be used to guide the research and formulation of the data collection tool. For the purpose of this research, the intrapersonal level will include individual factors, feelings and experiences. The interpersonal level will include relationships and social support. The institutional level will address health system factors, and the community level will include beliefs and cultural

and environmental influences. The policy level will not be explicitly explored due to the scope of this research.

4.2 Population and sample:

The study will take place at the Groote Schuur Colposcopy clinic. Groote Schuur Hospital (GSH) is one of the main referral centres for colposcopy services in Cape Town and serves a wide catchment area. Colposcopy clients will be recruited from the colposcopy clinic. Health care providers from the two main primary health care referring clinics viz. Cross Roads Clinic and Nolungile Day Hospital will be included in the study.

4.3 Sampling and recruitment:

A total of 24 female colposcopy clients 18 years and older will be selected. Respondents will comprise of 12 colposcopy attendees and 12 non-attendees. Non-attendees will be identified by reviewing the colposcopy clinic diary in consultation with the administration assistant. Clients that have not attended their appointment date will be telephonically contacted to participate in the study. Verbal consent will be obtained followed by a telephonic interview. New colposcopy clinic attendees at the colposcopy clinic will be recruited and interviewed on site. Clients will be purposively selected according to the inclusion criteria. Since the purpose is to collect data rich in depth, the final sample size will also be determined when a point of saturation has been reached [37].

Health provider interviews will comprise of eight participants:

a.) Three health care providers from the GSH colposcopy clinic: one colposcopist, the head of colposcopy clinic and a colposcopy nurse.

b.) The administrative assistant at the GSH cytology laboratory who makes the colposcopy bookings based on the Pap smear results.

c.) Providers from the two primary clinics. This will include the clinic manager and a nurse who performs Pap smears (cervical screening) from each of the clinics.

The providers will be purposively selected in order to gain insight into the barriers and facilitators to colposcopy clinic attendance. Providers will be recruited to participate in the study and consent will be obtained.

A pilot study will be done with two colposcopy clients attending the colposcopy clinic. In-depth interviews will be conducted to test the interview guide and to ensure participants' understanding of the questions. The pilot will also give input on the duration of the interview and an idea of the data analysis.

Inclusion criteria for clients:

- Women 18 years and older
- Referred to colposcopy due to an abnormal Pap smear result
- First time colposcopy attendee
- Ability to comprehend and communicate in English or Afrikaans
- Ability to provide consent

Exclusion criteria:

- Women younger than 18 years of age
- Previous cervical cancer
- Unable to speak and understand English or Afrikaans

Inclusion criteria for health care providers or key informants:

-Involved in some way in providing colposcopy services to patients

4.4 Data collection:

In-depth, individual, face-to-face interviews will be conducted with clients attending the colposcopy clinic, and telephonic, in-depth interviews with non-attendees. In-depth interviews were chosen as it is useful to explore personal experiences and perspectives on sensitive issues as well as ensuring confidentiality due to interviews being one on one [37]. Client interviews will be semi-structured using an interview guide (Addendum 1) with open-ended questions. This will allow for some flexibility, but also provide structure to the interview [38]. Client files will be reviewed for information regarding the date of the Pap smear, the Pap smear result and the referring clinic. An information sheet

(Addendum 2) will be used to collect demographic information including age; employment status; level of education; number of children; and marital status.

Interviews will take about forty five minutes each and involve questions covering individual, interpersonal, health system and community factors relating to colposcopy attendance as outlined by the ecological model [35] and the literature [24]. Individual factors will include, questions involving personal factors such as: client experiences; feelings; and knowledge of colposcopy, cervical cancer, and Pap smears. Interpersonal factors will include questions on social and family support. Health system factors will include questions on scheduling of the colposcopy appointment and provider communication. Community factors will include questions involving culture and beliefs. Interviews will be recorded with permission of respondents. These interviews will be conducted in a quiet room at the colposcopy clinic to ensure privacy.

In-depth individual interviews with health care providers at the colposcopy clinic and the referral clinics will be conducted using an interview guide (Addendum 3, 4, 5 & 6) with open ended questions. Interviews will cover questions relating to barriers and facilitators to colposcopy attendance from a provider's point of view. The duration of provider interviews will be about 30-40 minutes. Interviews will take place in a room at the colposcopy clinic and at the referring clinics for clinic staff. All interviews will be conducted by the main researcher in English or Afrikaans.

4.5 Data management:

All interviews will be recorded with a digital recorder with client and provider consent. In addition, field notes will be taken by the researcher. All recordings and field notes will be transcribed onto computer files using Microsoft Office. Any recordings and field notes in Afrikaans will first be transcribed, then translated onto computer files. Data will be transcribed as they are collected (iterative process). A copy of the files will be stored on a flash drive. All materials required for data collection, such as consent forms; interview guides; field notes; pens; and recorder; will be stored in big brown envelopes and labelled for convenience, on the day interviews are conducted. All materials and data collected will be stored in a secure place, which no one else will have access to, except the main researcher.

Each interviewee will be given an archival number which will be noted on each of the forms used for the interviews and stored in the envelopes. An archival log (Addendum 7) will be used as a data tracking form for interviews.

4.6 Data analysis:

The transcribed data from interviews and field notes will be entered into a qualitative computer software package, Atlas Ti version 6 (Scientific Software Developments, Berlin, Germany). Thematic analysis will be used to analyse the data. Thematic analysis is a method whereby codes are derived from the data [39]. Codes are used to form basic themes, the basic themes are then clustered to form organising themes, which are more specific than basic themes and encompasses a set of ideas [40]. Organising themes are then clustered to form global themes which explain what the text as a whole is about [40]. Similarities and differences across the data will also be assessed. The software will be used to identify data that support the themes. All data will be collected and analysed by the main researcher. Any uncertainties about themes and analysis will be discussed with a supervisor and co-supervisor to ensure accuracy. The co-supervisor will check themes by assessing a few transcripts to validate the correct interpretation of data.

4.7 Ethical considerations

The research complies with the Declaration of Helsinki (2008). The proposal will be submitted to the University of Cape Town Health Sciences Human Research Ethics Committee for approval. Permission to conduct the study will also be obtained from the City of Cape Town Department of Health, GSH, and the referring primary health care facilities.

Participant consent will be obtained on recruitment. A consent form will be provided for client attendees at the colposcopy clinic, as well as for providers. All information with regard to the procedure and details of the study will be provided on the consent form attached in the appendix (Addendum 8 & 9).

Verbal consent will be obtained telephonically from the non-attendee clients. To respect autonomy, participation in the study is voluntary and participants may decline to participate. Participants will not be penalised for declining and will still

receive all services entitled to them. They will be informed that they may withdraw from the study at any stage without penalty.

If participants agree to participate, all information collected will be strictly confidential and will only be shared with the supervisor and co-supervisor. To maintain anonymity participants' names will not be recorded, but rather, each will be given a study number. For the purpose of telephonic interviews, names of potential clients will be taken down from the colposcopy register, but, as telephonic interviews are completed names will be erased and replaced by a study number. If participants do not want the interview to be recorded, recordings will be stopped.

There are no foreseeable risks involved in participating in the study except that it may induce questions of uncertainty or queries with regard to the procedure, which can be addressed by the colposcopist. There are no direct benefits for participating, except that clients will be given a light refreshment. The results of the study can assist the wider community and provide better insight into how colposcopy services can be improved, to ensure that more women attend their follow-up appointments. To ensure accountability participants will be provided with the number of the UCT Human Research Ethics Committee and the main researcher, whom they may feel free to contact if they have any queries with regard to the study.

4.8 Limitations:

The study is being conducted at one tertiary hospital colposcopy clinic due to feasibility and time constraints and this could limit generalisation of results. Clients that speak only Xhosa will be excluded, as the researcher does not speak Xhosa and has chosen to conduct all interviews. The expected sample size may not be achieved; either due to respondents not fulfilling inclusion criteria, not attending appointments or being uncontactable, particularly, the clients being telephonically interviewed. Every effort will however be made to obtain contact numbers even if it necessitates contacting the referring clinic and asking for contact numbers. Data collected and analysed by one researcher could introduce researcher bias, but, data analysis will be discussed with a co-supervisor.

4.9 Generalisability

Qualitative research is not primarily concerned with results that are generalisable, but, the results from this study can be applicable to similar contexts in South Africa, where women are from low socio-economic backgrounds and users of government services.

4.10 Reflexivity

The principal researcher has a physiotherapy background with an interest in women's health and experience in clinical physiotherapy and rehabilitation. Having this background will assist in understanding clients' experiences in the hospital setting. To ensure reflexivity the researcher's ideas and thoughts will be separately recorded from participants' views.

5. Data Logistics:

5.1 Research team

All data will be collected, transcribed and analysed by the main researcher. The write up and dissemination of results will also be the responsibility of the main researcher. A supervisor will oversee the research project and a co-supervisor with experience in qualitative research will provide input with the analysis.

6. Write up and Dissemination:

Once the results have been analysed and written up, a meeting with health authorities will be arranged. Management and health providers from the colposcopy clinic and the two referring clinics will be invited to attend a presentation of the research results. It is intended that the research be presented to the Western Cape Provincial Department of Health to provide feedback on the research results. An electronic copy of the results will also be sent to the health care facilities included in the study.

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PART B: LITERATURE REVIEW

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Barriers and Facilitators to Colposcopy Attendance Following an Abnormal Pap Smear Result

1. Introduction

The objective of this literature review is to summarise key issues relating to challenges in the implementation of cervical cancer screening programmes in developing countries, particularly South Africa, with a focus on barriers and facilitators to follow-up of abnormal Papanicolaou (Pap) smear results. The literature review includes the following:

- The burden of cervical cancer in developed and developing countries.
- The prevention of cervical cancer, including the natural history of cervical cancer and primary and secondary prevention.
- Barriers and facilitators to follow-up of an abnormal Pap smear, including individual, psychosocial, health system and community factors.

An online journal search was conducted in Scopus, Pubmed, Medline and Google Scholar for articles relating to barriers and facilitators to the follow-up of abnormal Pap smear results. The World Wide Web was used to search the grey literature. Search terms included “cervical cancer AND risk factors”; “cervical cancer AND natural history”; “barriers OR non-adherence AND colposcopy follow-up”; “adherence OR loss to follow-up and colposcopy”, “abnormal Pap smear follow-up”; and “adherence AND cervical cancer screening follow-up”. Publications from 1978 to 2013 were selected from the above search engines. Articles were scanned by reading the abstracts. If the abstracts included any terms relating to barriers or facilitators to colposcopy attendance or follow-up of an abnormal Pap smear, it was selected for the review. Articles in which follow-up care had not included a colposcopy assessment were excluded. The reference lists of journal articles were used to identify additional articles. Qualitative and quantitative articles as well as articles from developing and developed countries were included to compare factors influencing colposcopy adherence between the different countries.

2. Burden of Disease

Cervical cancer remains a public health problem, particularly in developing countries. It is the second most common cancer following breast cancer, among women globally [1]. In 2012 there were an estimated 527 624 new cervical cancer cases and 265 653 deaths [2], with more than 85% of cases occurring in developing countries [3]. Cervical cancer comprised 9% of all cancer cases and 8% of all cancer deaths among women worldwide in 2008 [4]. The greatest cervical cancer burden occurs in sub-Saharan Africa, South America and South-Central Asia with age standardised incidence rates (ASIR) in these regions ranging between 24 to 34 per 100 000 women [3, 5].

In developed countries, mortality and morbidity associated with cervical cancer has decreased, due to the successful implementation of organised cytology-based screening programmes [6] in which precancerous lesions are detected and treated [7]. A sharp decline in cervical cancer mortality has been seen in Nordic countries, due to the widespread implementation of organised screening programmes [8, 9]. In Iceland, the age standardised mortality rate (ASMR) for cervical cancer decreased from 23.1 per 100 000 in the late 1960s to 14.6 per 1000 000 in the early 1970s [10]. For the period 1965-1981, mortality due to cervical cancer dropped by 80% in Iceland, 50% in Finland, 34% in Sweden and 10% in Norway [8]. The greatest impact in mortality rates was achieved in Iceland, due to the widest coverage of the programme [9].

The effectiveness of an organised cervical screening programme was also observed in England. After implementation of the programme, screening coverage increased from 45% in 1988 to 85% in 1994 [11]. Cervical cancer incidence dropped from 16 per 100 000 women in the 1980s to 10 per 100 000 women in 1994 and mortality decreased by nearly half over a ten year period (6.1 per 100 000 in 1987 to 3.7 per 100 000 in 1997) [11] .

These findings support the view that the decline in cervical cancer incidence and mortality rates in developed countries were due to organised screening programmes including a high screening coverage.

In contrast, in developing countries the incidence of cervical cancer remains high due to a lack of screening or poorly organised screening programmes [12]. Many

of the health providers in developing countries display a lack of knowledge about the aetiology of cervical cancer thereby influencing patient management [13, 14]. In an Asian study, 56% of providers associated poor personal hygiene as a cause of cervical cancer [13].

There are no organised cervical screening programmes in sub-Saharan Africa apart from South Africa [12]. Cervical screening in sub-Saharan Africa favours younger women accessing gynaecological and antenatal clinics and often does not reach older women who are at higher risk [15, 16].

An analysis of time trends indicates that cervical cancer incidence remains high in sub-Saharan Africa [17]. In 1990 the ASIR per 100 000 women was 40.4 in Southern Africa, 37.4 in Eastern Africa and 26.2 in Western Africa [17]. In Southern and Eastern Africa incidence rates have decreased, but are still high compared to developed countries, with an ASIR per 100 00 women of 26.8 in Southern Africa and 33.7 in Eastern Africa in 2008 [3] . In Western Africa, the ASIR has increased to 34.5 per 100 000 women in 2008 [3]. The consistently high cervical cancer incidence could be partially due to a low population screening coverage and poor access to treatment for precancerous lesions in most parts of Africa [16, 18]. In Africa, the highest cervical cancer mortality rate is in Southern Africa with an ASMR of 14.8 per 100 000 in 2008 [3].

Data on cervical screening coverage rates are lacking in Africa. Very limited cervical screening occurs in most parts of Africa [18]. In 1997 a study conducted in Uganda, Tanzania, Lesotho, Kenya and Zimbabwe reported that, across the five countries, on average only four Pap smears per month were performed at the primary level, twenty per month at the district and provincial hospitals and 86 per month at the tertiary hospitals [16]. An absence in policy guidelines, a shortage of laboratory infrastructure, limited trained health providers, a lack of resources and other health priorities contributed to this low screening coverage.

In South Africa, cervical cancer is the second leading cause of cancer among women [1]. It is estimated that 5 743 new cases and 3 027 deaths occurred in 2008, with an ASIR of 26.6 per 100 000 women [5]. The highest incidence rate was among black women with an ASIR of 29.46 per 100 000 compared to 13.5 per 100 000 in white women in 2006 [19]. The number of new cases and deaths of

cervical cancer in South Africa are projected to increase by more than 21% and 27% respectively by 2025 if current trends continue [1]. For example incidence is projected to increase from 5743 in 2008 to 7329 in 2025.

An analysis of time trends shows there has been no marked decrease in cervical cancer incidence in South Africa. Between 1993 and 1995, the ASIR for cervical cancer was 22 per 100 000 women, though the incidence in black women was the highest, with an ASIR of 27 per 100 000 women [20]. Cytology screening in the public sector was mainly available in antenatal and family planning clinics serving primarily younger women at lower risk [21]. The high cervical cancer incidence, particularly among black women, is perhaps due to the unequal access to cervical screening during the apartheid era [7]. Since 1993 the incidence of cervical cancer has been consistently high, with an ASIR of 28.7 per 100 000 women reported in 1999 [22]. A marginal decrease was, however, observed in the early 2000s, but the incidence was still high compared to developed countries, with an ASIR of 22.75 per 100 000 women reported in 2003 [23]. Whether this was a true decrease or difficulties regarding the accuracy of the National Cancer Registry data are not known.

In summary, cervical cancer remains a major burden of disease in South Africa and other developing countries in Africa, due to a lack of, or poorly organised, screening programmes.

3. Prevention of Cervical Cancer

3.1 Natural history of cervical cancer

The natural history of cervical cancer (outlined in Figure 1) serves as a basis for the development of prevention strategies. Cervical cancer is caused by persistent infection of the cervix with high-risk human papillomavirus (HPV) which is transmitted sexually [24]. HPV has been recognised as a necessary but not sufficient cause of cervical cancer [25]. HPV infection may resolve spontaneously or develop into low grade squamous intraepithelial lesions (LSILs) [26]. The majority of LSILs resolve within two to three years [27]. However, a LSIL can progress into a high grade squamous intraepithelial lesion (HSIL) [28]. The majority of HSILs will advance to invasive cancer [27]. The progression from

precursor lesions to invasive cancer occurs over a period of 10 to 20 years [29]. The slow advance from precancerous to cancerous lesions allows for sufficient time to intervene and prevent the development of cervical cancer [30].

Risk factors influencing the progression to cervical cancer include co-infection with other sexually transmitted infections such as chlamydia trachomatis, neisseria gonorrhoea, human immunodeficiency virus (HIV) [31] and herpes simplex type 2 [32]; long term contraceptive use (> 5 years) [33]; cigarette smoking [34] and multiparity [35].

HIV increases the risk of persistent HPV infection, cervical precancerous lesions and cervical cancer [36, 37]. South African studies have shown that HIV positive women are five times more likely to be infected with HPV than HIV negative women [36, 38]. Infection with high risk HPV has been associated with immune suppression [37]. Research has also shown that HIV positive women are more likely to present with invasive cervical cancer ten years earlier than HIV negative women [39]. The link between HPV and HIV further highlights the importance of cervical screening and follow up of HIV positive women with abnormal Pap smears. This is particularly important to South Africa due to the HIV burden (5.7 million adults) with more than 50% of adults infected with HIV being women [40].

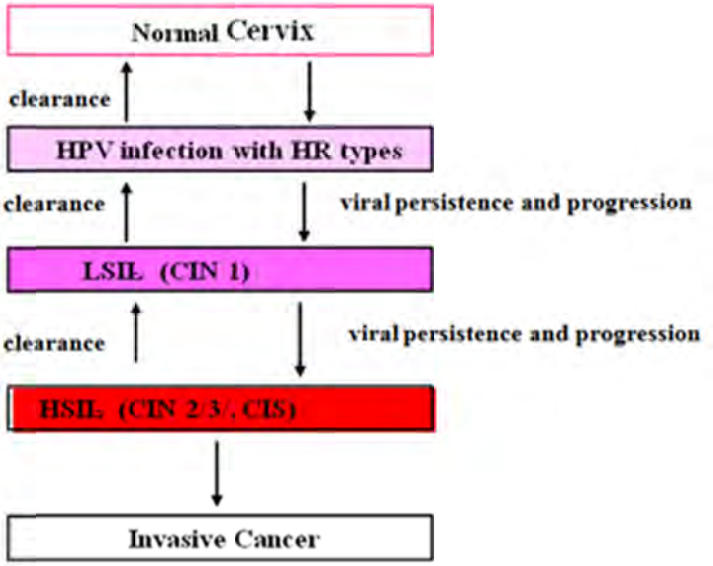

Figure 1. Natural history of cervical cancer [41]

CIS, carcinoma in situ; CIN, cervical intraepithelial neoplasia; HPV, Human Papilloma virus; LSIL, low grade squamous intraepithelial lesion; HSIL, high grade squamous intraepithelial lesion; HR, high risk.

3.2 Primary prevention

Primary prevention of cervical cancer involves protection against HPV infection [7]. Studies have shown that the HPV vaccine is an effective primary prevention option [42, 43]. The vaccine offers almost full protection against the two most common types of persistent HPV infection (16 and 18) associated with cervical cancer [42]. However, the vaccine is only effective if women are vaccinated before they are infected with the HPV [42]. HPV vaccination, even with high coverage, will only prevent 70% of cervical cancer [43]. Secondary prevention through cervical screening remains essential for women who are already exposed to the HPV infection and to other HPV types [43].

The Department of Health has recently launched a national vaccination programme in South African government schools, providing the HPV vaccine to grade four girls, nine years and older [44]. However, some girls in low resource areas and not attending schools may not get vaccinated [45].

3.3 Secondary prevention

Secondary prevention stops the progression of disease from precursor lesions to invasive cancer [46]. Various secondary screening methods have been used for the detection of cervical cancer precursor lesions. The most commonly used tests are the Pap smear, HPV DNA testing and visual inspection with acetic acid (VIA) [47]. The Pap smear remains the most widely used screening test and involves collecting endocervical cells with a spatula or brush for microscopic examination for detection of precursor lesions [46].

Women with abnormal smears (HSILs and persistent LSILs) require a colposcopy assessment [12]. Colposcopy is a specialised procedure using a colposcope with a strong light to examine the uterine cervix for cervical abnormalities; it allows a biopsy to be obtained for a histological diagnosis [48]. Follow-up and treatment of precursor lesions are critical steps in the secondary prevention of cervical cancer.

Developing countries face many challenges implementing an effective cytology-based screening programme [12]. Some of these challenges include: human resource shortages, resource constraints, poorly functioning health systems [49], a lack of access to health services particularly by women of low socioeconomic status (SES) living in rural or urban areas, and competing health priorities [16, 50]. A key challenge is poor colposcopy clinic attendance following an abnormal Pap smear [51].

A National Cervical Cancer Screening Policy was introduced in South Africa in 2000 [52]. The screening policy states that women between the ages of 30-60 years are entitled to three free Pap smears in their lifetime, ten years apart. The objective of the policy is to decrease the number of new cases of cervical cancer by identifying and treating the early stages of the disease. The goal of the policy is to screen at least 70% of women within the target age within 10 years of commencing the programme. Theoretically, if well implemented, the policy has the potential to reduce cervical cancer incidence by 67% [53]. South Africa is yet to reach this goal. Compared to the United States Cervical Cancer Screening Guidelines, recommends that women between the ages of 21-65 years be screened with cytology every 3 years [54]. Screening every 3 years has been associated

with a life time risk of cancer of approximately 5 to 8 incident cases per 1000 women and a life time risk of death of 0.05 per 1000 women [54].

Over the past few years cervical screening coverage has gradually increased in South Africa from 18% in 2003 [55] to 55% in 2011 [56]. Implementation of the policy has been challenging due to a lack of provider knowledge about the screening policy, cervical cancer, and the management of clients with abnormal Pap smears [50, 57]; poor community knowledge and awareness regarding Pap smears and cervical cancer; low literacy levels [58-60]; fear of the Pap smear procedure and not feeling ill [61] were among a few reasons reported.

The ultimate goal of cervical screening is the prevention of cervical cancer; this is only beneficial if women with abnormal smears are appropriately investigated (at the colposcopy clinic) and treated [62]. If women with abnormal Pap smears do not attend follow-up sessions, this will result in a decrease in screening effectiveness, reduce the efficiency of health care resources, and increase programme costs [63].

Loss to follow-up, non-adherence and default to follow up an abnormal Pap smear have been used interchangeably in the literature and have been defined in the proposal (Section A page 3). Loss to follow-up (LTFU) rates of between 33% and 58% of women with abnormal Pap smears have been reported in South Africa [50, 64-66]. A study in Gauteng identified LTFU to be over 50% among women who were referred to colposcopy with high grade lesions [66]. Reasons that woman were lost to follow up were due to poor health system performances such as poor record keeping and appointment making procedures, and inadequate capacity of the colposcopy services. In this study, client reasons for non-attendance were, however, not explored.

Similar findings were documented in The Cervical Health Implementation Project (CHIP), conducted between 2001 and 2003 in three provinces in South Africa [50]. This study found that 50% of women with HSIL who were referred to colposcopy were lost to follow up [50]. The high rate of LTFU in CHIP was partially attributed to inadequate client tracking. A slightly lower rate was detected in another local study in the Western Cape, South Africa, with a 33% LTFU among women referred for colposcopy in 2009 [65]. These studies have

provided some quantitative data on the extent of poor colposcopy clinic attendance. However, there is limited information on reasons for poor attendance in South Africa.

In summary, primary and secondary prevention strategies for cervical cancer exist. The main objective of secondary prevention is the early detection and treatment of precursor lesions. Unless precursor lesions are followed up, screening efforts are futile. Secondary prevention will remain an important strategy for many years. LTFU of women with abnormal Pap smears remains a significant challenge in South Africa. The next section reviews the literature on barriers and facilitators to follow-up of abnormal Pap smears.

4. Follow-up of Abnormal Pap Smears: Barriers and Facilitators

In a systematic review from the US, Eggleston et al [67] reported on adherence rates to follow-up of an abnormal Pap smear of between 27% and 90%. This wide range is due to the different definitions used in the literature. In Ontario, Canada, where the requisite time for follow-up of high grade abnormalities (colposcopy or treatment) is two to six months, adherence rates were 60% at three months and 83% at six months [68]. A lower adherence rate at three months is suggested to be due to system issues including a lack of resources to meet the demand of women requiring follow up of high grade lesions. The South African screening policy does not provide guidance on the requisite time between an abnormal Pap smear diagnosis and time seen at the colposcopy clinic [52].

Barriers and facilitators to colposcopy attendance have been reported to be influenced by multiple interrelating individual, psychosocial, health systems and community factors [67, 69]. Individual factors include socio-demographic and patient level factors [67, 69]. Psychosocial factors include clients' feelings and experiences [67, 70]. Health system factors include provider communication, administration procedures and client tracing [71]. Community factors include population characteristics, and cultural values and beliefs [69, 72].

4.1 Individual patient factors

Studies investigating barriers to follow-up of an abnormal Pap smear (colposcopy or treatment) found lesion severity [67, 73, 74], age, level of knowledge,

educational level, SES and employment to significantly influence follow-up attendance [67, 68, 75-77].

Women with HSIL or atypical glandular cells of undetermined significance (AGCUS) are more likely to attend follow-up appointments (repeat Pap smear or colposcopy) for an abnormal Pap smear compared to women with low grade lesions [73, 74]. In a study conducted in the US follow-up attendance at three months was 76% in women with HSIL compared to 57% in women with LSIL [78]. In a cross-sectional study from the US, lesion severity was, however, not significantly associated with adherence to recommended follow-up care [79]. It has been suggested that providers and patients view low grade lesions as less important to follow up compared to more severe lesions (adenocarcinoma and HSIL) [67, 74].

Age is a factor associated with follow-up attendance. Either being very young (<30 years) or older (>55 years) has been shown to negatively influence follow-up (colposcopy or treatment) of an abnormal Pap smear [68, 69, 75, 77]. In a cohort study in the United Kingdom (UK), 6.7% of women defaulted colposcopy, of which 62% were between 20-29 years compared to 39% between 30-59 years [75]. Being very young was associated with a lack of knowledge or understanding of the purpose of screening and follow-up care, as well as being less exposed to gynaecological care [75]. Reasons for older women being non-adherent are not well understood, but a US study reported that older women were past the childbearing stage and were therefore less concerned about gynaecological conditions [69]. Further research regarding the influence of age on colposcopy attendance is required in South Africa, in order to ensure that women of all ages access colposcopy services.

Colposcopy non-adherence is more common among women with a low SES and a lack of knowledge of Pap smears, cervical cancer and the colposcopy procedure [68, 75-77]. A retrospective cohort study conducted in the US showed that 13% of women delayed care for an abnormal Pap smear partly due to a lack of knowledge of Pap smears and cervical cancer [80]. The women who delayed care had a lower educational level and income than the women who attended follow-up care. Similarly, studies from the US and the UK demonstrated that women with lower

levels of education were more likely to default colposcopy services than women with a post-school education [75, 76, 81]. In the same UK study, unemployed women were 2.7 times more likely to default colposcopy than women who were employed [75]. Women with a low SES often have a lack of access to health care services, lower literacy levels, limited knowledge of disease, and are at a greater risk of cervical cancer [18, 82]. However, other studies found no association between socio-demographic factors and follow-up attendance [51, 63, 79]. Studies have utilised different study designs and methods, possibly accounting for these differences.

Research exploring knowledge of women with abnormal Pap smears, referred for colposcopy is not available in South Africa. This information would assist with recommendations to improve colposcopy attendance.

Personal factors influencing colposcopy attendance include: family responsibility, disruption of work, and transport difficulties [69, 71, 81]. In a qualitative study, health care providers serving rural communities from high risk areas in the US reported that patients often had to choose between daily necessities such as petrol, transport, childcare costs and seeking preventative care [72]. Non-attendance at colposcopy due to transport difficulties has been reported in South African studies [50, 65, 69]. Blankenberg [65] illustrated an 18% increase uptake in colposcopy attendance at a locally implemented colposcopy clinic in the Western Cape, South Africa, compared to when patients were referred to a distant referral hospital.

It is important to identify whether women referred for colposcopy experience similar or different personal barriers in South Africa, so that colposcopy services can be made more accessible to women.

4.2 Psychosocial factors

Attending a colposcopy appointment to investigate an abnormal Pap smear result has been associated with psychological distress [63, 70, 83, 84] and colposcopy non-adherence [69, 75, 76, 80]. The most common psychosocial factors related to colposcopy non-adherence were fear and anxiety [63, 67, 69, 71]. This includes fear and anxiety with regard to the procedure, fear of the unknown, fear of having cancer, anxiety as a result of not understanding the meaning of the Pap smear

result [71, 76, 80, 81, 85], and fear of not being able to take care of oneself or dependants due to ill health [69].

Fear and anxiety have been described as both a barrier and a facilitator to follow-up (colposcopy or treatment) attendance [69, 76]. In qualitative studies from the US and the UK, a fear of cancer and fear of the unknown had a negative influence on return for follow-up Pap smears, colposcopy appointments or treatment [69, 76, 86]. Women with a family history of cancer were particularly fearful [69, 86]. In the US study, Abercrombie [86] reported that HIV positive women were fearful of an abnormal Pap smear result because of a greater risk of developing cervical cancer. For these women, the possibility of having another life-threatening disease was alarming and contributed to non-attendance. In comparison to rural Appalachian women in the US, fear evolving from a family history of cancer, along with the knowledge of the importance of follow-up care, motivated a group of women to attend their appointments [69].

In a study conducted in Soweto, South Africa, more than half the women presenting at a colposcopy clinic had elevated anxiety scores [83]. Similar findings were reported in Swedish and UK studies [70, 84]. In the Swedish study, anxiety was significantly associated with a score rated as "unsatisfactory" in economic, living and working conditions [84]. In the South African study, socio-demographic factors were not significantly associated with elevated levels of anxiety [83].

It is evident from these findings that women referred for colposcopy experience fear and anxiety. Reasons contributing to women's fears related to a colposcopy referral need to be further explored in South Africa, so that clients' fears can be addressed.

Fear that the colposcopy procedure would compromise fertility and cause a miscarriage in pregnancy have also been reported as reasons for non-attendance among socially disadvantaged women in developed and developing countries [51, 69, 76]. In a Nigerian study, 33% of women refused to attend a colposcopy appointment, mainly due to fear that the procedure would affect future fertility [51]. The women who refused colposcopy were mainly young and nulliparous and resorted to spiritual help from spiritual leaders and church pastors. In some

African cultures and religions in Nigeria and South Africa, children are seen as a form of economic and social security for the family as well as a continuation of the family name [87, 88]. Anything that would jeopardise pregnancy is therefore avoided [51]. This indicates the importance of determining women's perceptions of fertility in relation to attending a colposcopy procedure. This will aid in the planning of education strategies to educate women on the safety of the colposcopy procedure.

Anxiety is not only influenced by factual information about the colposcopy procedure, but also by experience, attitudes, concerns and beliefs [89]. In a study conducted in the UK, women reported that a positive, supportive staff attitude had improved their colposcopy experience and decreased their levels of anxiety [70]. In another study conducted in the US, social support received by women in response to an abnormal Pap smear result had improved adherence to follow-up care threefold [90]. The role of social support in facilitating colposcopy attendance has not been explored in South Africa.

Limited South African data on the psychosocial factors influencing colposcopy attendance are available.

4.3 Health system factors

Studies in the US and UK have highlighted the following provider factors that influenced colposcopy attendance: the gender of the colposcopist, with preference for a female colposcopist [70, 76]; and poor provider communication with regard to the procedure, explanation of the results and the diagnosis [67, 70, 71, 76]. A US study among a low income population reported that women were more likely to follow up (with colposcopy or repeat Pap smear) when the results and treatment plan were explained and when colposcopy services were offered at the same clinic where the patient had had the Pap smear [91].

In a South African study the long waiting time for a colposcopy appointment due to limited colposcopy services was identified as a barrier to colposcopy attendance [66]. Other factors impacting on colposcopy attendance in South Africa include clients not being informed of Pap smear results; inadequate recordkeeping; failure to book colposcopy appointments; and a lack of client tracking [65, 66].

In an attempt to decrease LTFU in women with abnormal Pap smears, various patient tracking interventions have been introduced in different countries. In a randomised control trial in California, client tracking comprised of a nurse consultant that followed-up on clients with an abnormal Pap smear [92]. Tracking was aided by a computerised database which detected follow-up appointments within a certain time period. All clients in the trial were informed telephonically and in writing about an appointment for a colposcopy or repeat Pap smear. The intervention group received a reminder call before the follow-up appointment and, if the patient did not attend, the client was recalled to reschedule the appointment and the importance of attendance emphasised. The intervention group was four times as likely to attend a follow-up appointment at six months compared to the standard care group. Telephone reminders assisted by a computerised tracking database could be an effective strategy in tracing colposcopy clients in South Africa, if sufficient resources were allocated. This strategy would require functioning telephone systems, computerized systems and human resources.

In another study conducted in a low resource setting in Cape Town, South Africa, LTFU of women for repeat cervical screening appointments significantly decreased by introducing community health worker (CHW) visits [62]. CHWs visited women at their homes if they had not attended their scheduled screening appointments. The home visits were more successful when they were done closer to the initial appointment date. LTFU was reduced by 15%, 29% and 26% at six, 12 and 24 months respectively. Organised CHW visits could be utilised to trace non-adherent colposcopy patients in South Africa, which would probably cost less than treatment for late stage disease. However, there are currently too few CHWs to meet this demand [93].

Approximately 80% of South Africans consult traditional healers in conjunction with western medicine for their health related needs [94]. In a South African study, traditional healers expressed their willingness to exchange information and collaborate with western doctors in preventing cervical cancer [95]. By collaborating with western health care providers, traditional healers could be a valuable asset in encouraging women to attend colposcopy.

4.4 Community factors

Community factors identified in studies from the US and Nigeria as influencing adherence to follow-up care (repeat Pap smear, colposcopy or treatment) for an abnormal Pap smear include: patient concerns regarding confidentiality in close knit communities, particularly in rural areas; lack of community awareness about seeking follow-up care; and cultural beliefs [51, 69].

South African data on community factors influencing cervical screening practises are available [96, 97], but information on community factors impacting on colposcopy attendance are lacking. Cultural barriers and beliefs influencing cervical screening involve stigma associated with cervical cancer; embarrassment [97]; "opening the legs" being seen as shameful particularly by Xhosa-speaking women to whom it is unseemly for an older women to expose herself to a younger provider; and the belief that cervical cancer was caused by witchcraft [96].

In summary, colposcopy non-adherence remains a challenge even where the service is available. Women are faced with many barriers in accessing colposcopy services. The majority of studies are, however, quantitative and conducted in developed countries. Qualitative studies are important in understanding reasons for poor colposcopy adherence.

5. Conclusion

Although cervical cancer is preventable, incidence and mortality rates remain high. Treating abnormal lesions detected on cervical screening can contribute towards decreasing incidence and morbidity associated with cervical cancer. Poor colposcopy clinic adherence is a major problem in developing countries and contributes to a decrease in screening effectiveness. Qualitative research exploring reasons for poor colposcopy attendance in South Africa is required. Little is known about women's knowledge and experiences of abnormal Pap smears, cervical cancer and the colposcopy procedure in South Africa. This research will provide additional insights to better understand the factors influencing women's attendance at colposcopy. It could also inform health care providers and policymakers about areas of system improvements and possible targeted interventions that could increase colposcopy attendance.

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Part C: JOURNAL MANUSCRIPT

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Barriers and facilitators to colposcopy attendance following an abnormal Pap smear in South Africa: A qualitative study exploring client and provider perspectives

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Barriers and facilitators to colposcopy attendance following an abnormal Pap smear in South Africa: A qualitative study exploring client and provider perspectives

Abstract

Background: Colposcopy adherence following an abnormal Papanicolaou (Pap) smear is a major problem in low- and middle-income countries, including South Africa. Cytology-based screening is only beneficial if women with abnormal Pap smears are followed up at the colposcopy clinic and treated to prevent progression to cervical cancer. The purpose of this study was to explore barriers and facilitators to colposcopy attendance following an abnormal Pap smear result.

Methods: A qualitative, exploratory study was conducted at a public sector tertiary hospital colposcopy clinic and at two primary health care clinics in Cape Town, South Africa. The study was conducted between May and August 2013. Data collection included 32 semi-structured interviews: 12 face-to-face interviews with colposcopy clinic attendees, 12 telephonic interviews with colposcopy clinic non-attendees and 8 face-to-face interviews with health care providers. Client interviews explored barriers and facilitators to colposcopy attendance; knowledge and experiences of Pap smears, cervical cancer and the colposcopy procedure; scheduling of colposcopy appointments; provider communication; reasons for non-attendance; and community support and beliefs. Provider interviews explored barriers and facilitators to colposcopy attendance from a provider's perspective; the colposcopy referral process; and provider challenges in the provision of Pap smear or colposcopy services. Interview data were analysed using thematic analyses.

Results: The main barriers influencing colposcopy attendance were: poor levels of knowledge of the importance of a Pap smear and the colposcopy procedure; a lack of awareness of cervical cancer as a disease; a fear of cancer; the asymptomatic nature of the disease; and transport costs. Health system barriers included clients not informed of colposcopy appointments and therefore they did not attend; a disjointed system of colposcopy scheduling; and staff shortages which resulted in less time for client tracking. Factors which promoted colposcopy attendance included experiencing symptoms; a family history of cancer due to the experience with death; colposcopy services situated closer to clients; and social support received from family members.

Conclusion: Colposcopy attendance could be improved through interventions that address poor client knowledge, improve provider-client communication, bring colposcopy services close to clients and simplify the colposcopy appointment system.

Key words: cervical cancer, Pap smears, barriers, facilitators, colposcopy adherence, provider and patient perspectives, South Africa.

Background

Cervical cancer remains a public health burden, particularly in developing countries. It is the second most common cancer among women globally [1], with estimates of 527 624 new cervical cancer cases and 265 653 deaths worldwide in 2012 [2]. The majority of cases (more than 85%) occurred in developing countries in 2008 [3]. In South Africa, cervical cancer is the second most common cancer among women [1] with an age-standardised incidence rate (ASIR) of 24.7 per 100 000 women in 2006 [4]. The number of new cases and deaths of cervical cancer in South Africa are expected to increase by more than 21% and 27% respectively by 2025 if current trends continue [1]. For example incidence is projected to increase from 5743 in 2008 to 7329 in 2025.

A reduction in cervical cancer incidence and mortality has been successfully achieved in developed countries due to organised cytology-based screening programmes and early treatment of precancerous lesions [5]. In contrast, the incidence of cervical cancer in developing countries remains high due to a lack of screening or poorly organised screening programmes [6], with inadequate referral systems and treatment of abnormal Papanicolaou (Pap) smears [7].

The South African Cervical Screening Policy entitles women between the ages of 30 and 60 years to three free Pap smears in their lifetime, ten years apart [8]. The objective of the policy is to decrease the number of new cases of cervical cancer by identifying and treating the early stages of the disease. The policy guidelines state that abnormal Pap smears with high grade squamous intraepithelial lesions (HSIL), atypical glandular cells of undetermined significance (AGUS), or two consecutive Pap smears with persistent atypical squamous cells of undetermined

significance (ASCUS), or with low grade squamous intraepithelial lesions (LSIL), should be referred for a colposcopy assessment.

High rates of loss to follow-up (LTFU) or non-attendance at colposcopy clinics have been reported, particularly in low-income regions [7, 9-11]. LTFU rates of between 33% and 58% have been reported in South African studies [7, 11-13]. The ultimate goal of cervical screening, which is the prevention of cervical cancer, is only beneficial if women with abnormal smears are treated and followed up [14].

Studies have highlighted factors influencing women's attendance at colposcopy. However, the majority of these studies are international and quantitative. Factors influencing colposcopy attendance include individual, psychosocial, health system, community and cultural factors [15-18].

Limited South African data on the barriers and facilitators to colposcopy attendance following an abnormal Pap smear are available, particularly qualitative data. Little is known about women's knowledge and experiences of an abnormal Pap smear result, cervical cancer and the colposcopy procedure in a South African setting. In order to improve colposcopy adherence, a better understanding of the factors that influence women's attendance at colposcopy in South Africa is needed. This could inform health providers and policymakers about areas of system improvements and possible targeted interventions that could improve colposcopy attendance rates.

This study explored barriers and facilitators to colposcopy attendance following an abnormal Pap smear result. Perspectives of colposcopy clinic attendees, colposcopy clinic non-attendees and health care providers are presented.

Methods

Study design

A qualitative exploratory study was conducted, informed by McLeroy's ecological model [19], as a means to explore barriers and facilitators that women with abnormal Pap smears face when accessing colposcopy services. The model provided a framework to understanding health behaviour based on multiple interacting levels of influence [20], namely: the individual/intrapersonal level, which includes any individual characteristics such as knowledge and experiences; the interpersonal level, which includes social networks and social support structures; the organisational level, which includes how organisational institutions affect health behaviour; the community level, which includes beliefs and community influences; and the policy level, which includes laws and policy [19]. The policy level was not explored in this study.

Study setting

The study was conducted between May and August 2013 at a public sector, tertiary hospital colposcopy clinic and two primary health care clinics providing cervical screening services, in the greater Cape Town area, South Africa.

Organisation of Pap smear and colposcopy services

In Cape Town, Pap smears are usually performed by nurses at primary health care facilities and sent to a centrally located cytology laboratory. Colposcopy services are primarily offered at tertiary and a few secondary hospitals and performed by a gynaecologist. Clients referred to colposcopy services from the two clinics included in this study were mainly referred to the tertiary hospital. A few clients

were also referred to a recently established colposcopy clinic situated in close proximity to one of the primary health care clinics. Pap smear results are usually available two to four weeks after the smear is taken and these are sent via courier services to the respective clinics. Women receive a follow-up appointment from the clinic provider to collect their Pap smear results. Women with an abnormal result that has not been collected should be contacted by the clinic provider.

The system of colposcopy scheduling is complex and disjointed. Furthermore, methods used to inform women of Pap smear results and colposcopy appointments are not standardised.

Study population

A total of 32 in-depth interviews were conducted with participants selected from the three study sites. Participants were purposively selected to include 12 colposcopy clinic attendees, 12 colposcopy clinic non-attendees and eight health care providers. Colposcopy clinic attendees were identified as clients with an abnormal Pap smear result who had attended their colposcopy assessment, irrespective if it was a rescheduled appointment or not. Colposcopy clinic non-attendees were identified as clients with an abnormal Pap smear result who had failed to attend their colposcopy assessment.

English or Afrikaans speaking clients, 18 years and older and booked for a first colposcopy visit, were eligible for the study. Colposcopy clients were identified from clinic folders and recruited at the colposcopy clinic prior to their appointment. A list of clients who failed to attend their appointment was obtained from the colposcopy clinic tracing team. Where possible, attempts were made to contact non-attendees before the tracing team did. Non-attendees were

telephonically contacted from the day following a missed appointment. Attempts to contact clients were made six times before contact was discontinued.

Providers included the clinic manager and a nurse performing Pap smears from each of the primary health care clinics, two doctors and a nurse from the colposcopy clinic and an administrative assistant from the cytology laboratory.

Data collection

Individual interviews with attendees and providers took place in a private room. Non-attendees were telephonically interviewed. All interviews were conducted in English or Afrikaans by the principal researcher. Interviews lasted between 20 to 45 minutes for both providers and clients. Participant interviews were digitally recorded, translated where necessary and transcribed verbatim.

Interview guides were open-ended and semi-structured. Key issues explored in both the attendee and non-attendee interviews included: barriers and facilitators to colposcopy clinic attendance; knowledge and experiences of Pap smears, cervical cancer and the colposcopy procedure; the scheduling of colposcopy appointments; provider communication; and family and community support and beliefs. Non-attendees were further probed about reasons for non-attendance.

Client demographic information included age, educational level, employment status, marital status and number of children. Details of the Pap smear results were obtained from clients' clinic folders.

Provider interviews explored barriers and facilitators to colposcopy attendance from a provider's perspective; the colposcopy referral process; challenges in the provision of Pap smears or colposcopy services; and health system interventions to increase colposcopy compliance.

Ethical considerations

Written informed consent was obtained for the face-to-face interviews and verbal consent was obtained for the telephonic interviews. Confidentiality and anonymity were ensured. The study was approved by the University of Cape Town Health Sciences Human Research Ethics Committee and institutional approval was obtained from City Health Cape Town and the tertiary hospital management.

Data analysis

The data were collected and analysed by an iterative process. This allowed for further refining of questions and exploration of additional issues. Thematic analysis was used to analyse the data. Thematic analysis is a process whereby the data are coded, organised into themes and clustered to form more specific themes, which illustrate what the text as a whole is about [21]. A software package Atlas Ti version 6 (Scientific Software Developments, Berlin, Germany) was used to organise the data into codes and to support themes. The data were read several times for broad emerging themes which were further condensed into more specific themes. Analysis for similarities and differences took place within and across the data.

Results

The mean age of clients was 40.2 years (range 29-63 years), and was similar between the attendees and non-attendees. Eight (33.3%) of the clinic clients were married, two (8.3%) were widowed, ten (41.7%) were unmarried and four (16.7%) were divorced. Both the attendees and non-attendees had between one and four children. Thirteen (65%) of the clinic clients had completed grade twelve

and four (16.7%) had completed some form of post-secondary education. Half (50%) of the attendees and a third (33.3%) of the non-attendees were employed.

Themes identified as influencing colposcopy attendance included: levels of knowledge related to screening and cervical cancer; motivations associated with having a Pap smear and colposcopy attendance; fear and anxiety related to an abnormal Pap smear result and colposcopy procedure; personal factors including transport costs, work schedules and childcare responsibilities; health system factors including infrastructural barriers; and social support.

Knowledge levels

The majority of clients were unable to distinguish between cancer and cervical cancer. Attendees and non-attendees described cancer more broadly as a "dangerous disease", incurable if detected at a late stage and fatal. A few attendees and non-attendees reported having heard of cervical cancer or "cancer of the womb", but did not have detailed knowledge except that a hysterectomy could be performed if cancer was detected. Some clients were aware of other types of cancers such as breast, stomach, lung and oesophageal cancer. As reported by a clinic provider:

Women are not aware of cervical cancer, the type of cancer that they are aware of and afraid of is cancer of the oesophagus, cervical cancer they don't know.

Clients' awareness of cancer or cervical cancer were influenced by community or family experiences of cancer, for example, death resulting from cancer; by information relayed at the clinics or via the media. Clinic providers did not always distinguish between the terms cancer and cervical cancer and in many instances these terms were not adequately explained. This created an awareness of cancer or

cervical cancer, but a lack of detailed knowledge or understanding of the disease. As indicated by a non-attendee:

I heard at the clinic when they tell the people about cancer, they didn't explain thorough, but they encourage us to come to the clinic.

The majority of attendees and non-attendees had a similar understanding of the importance of a Pap smear. Pap smears were identified as important for the detection of cancer in the womb or to determine any diseases of the womb, for example, sexually transmitted infections (STIs). A few non-attendees did not know what a Pap smear was. Among the non-attendees, a lack of knowledge of the importance of a Pap smear was associated with a poor understanding of the implications of an abnormal Pap smear result and hence the purpose of follow-up.

Many attendees and non-attendees did not appear to understand the significance of an abnormal Pap smear result. Consequently, a few non-attendees were unable to differentiate between an infection and the abnormal Pap smear. This phenomenon was highlighted by a non-attendee:

When I went for the Pap smear she [nurse] *said she sees an infection thing….Now I don't know what it really is…..*

The majority of clients displayed a lack of knowledge about the colposcopy procedure. A lack of client understanding about the procedure and the Pap smear result was reported to be due to an inadequate explanation or no explanation given by primary level providers, as reported by an attendee:

The results of the Pap smear were not explained to me, they just said your results are out, they are referring you to the other hospital so that they can attend to you…

A colposcopy provider reported that part of the problem of non-attendance could be attributed to a lack of knowledge among primary level nurses about the natural history of cervical cancer and the management of precancerous lesions, thereby influencing patient counselling:

I think the problem is the vast majority of nurses doing Pap smears in the Cape don't even know themselves why they are doing Pap smears and they are not giving the patients the right information.... They tell the patient when they have a HSIL and most of them tell them that they have cancer. Others tell them that they have an infection but no one talks about pre-cancer and treatable etc. So I think the level of knowledge of health care providers at primary level is very poor and then patients are not getting the right message…

Misinformation about an abnormal Pap smear result and cervical cancer received from primary level providers resulted in clients being fearful. This situation was reported by a colposcopy provider:

By the time they get to me some of them have the "beverasies" (shakes), they think they are going to die in a week. So they are not being messaged correctly, that's part of the issue.... So I think it's the way we counsel patients and I think well-informed patients treated with respect….are going to be compliant.

A lack of client understanding about the result and the procedure was further influenced by difficulty comprehending the terminology used in the colposcopy letter. This phenomenon was demonstrated by an attendee:

She [nurse] *gave me a letter with the results, I didn't understand…I went to the internet cafe and took that big words and put it in there so that I can know what it is about.*

Motivations for Pap smears and colposcopy

Women experiencing symptoms such as uterine pain or irregular bleeding were more likely to attend colposcopy appointments than women who were asymptomatic and had had a Pap smear as part of a routine clinic check-up or a family planning service visit. Providers confirmed that a lack of symptoms made it difficult for women to understand the importance of Pap smear screening. The following was reported by a clinic provider:

Very few come for the Pap smear.... I think our people they only think that when they are sick, they get a medication. Things like Pap smear tests those things because they don't feel anything they don't really realise that it's also important.

An absence of symptoms also contributed to clients not seeing the value in returning for Pap smear results, as highlighted by a clinic provider:

Some say they got no pains, nothing, so there's no point in coming to collect the Pap smear results because she's not feeling anything.

Fear and anxiety

The majority of clients reported fear in response to an abnormal Pap smear result and the colposcopy procedure. Fear of the unknown led to feelings of

anxiety. Clients feared having cancer due to the association with it being a terminal disease. Poor understanding of the meaning of the Pap smear result contributed to clients' fears of having cancer. This view was demonstrated by a non-attendee:

When she called me I felt bad ... I cried, I thought, oh no I have cancer. I just felt bad, I felt down, I was not happy the whole day....

Among non-attendees, a fear of cancer or fear related to the result was not explicitly stated as a reason for non-attendance, but it was a concerning issue for clients. Clients' fears were influenced by the choice of words that providers used in notifying them of the results. Words such as "wound in uterus", "cancerous", and "positive results" were some of the terms used.

A clinic provider reported that some patients did not return for Pap smear results due to "fear of the unknown". Failure to return for results resulted in clients requiring colposcopy of being uninformed about a booked colposcopy appointment.

Feelings of fear were heightened by a family history of cancer, particularly cervical cancer, due to the distress experienced by the family member; death of a family member, or negative responses about cancer conveyed by others. Fear experienced in this context resulted in a greater likelihood of attending the colposcopy clinic. Concern for the future well-being of children had also prompted women to attend the colposcopy clinic, as reported by an attendee:

...Just because I have a child that's why I'm coming here [colposcopy clinic].

Lack of knowledge about the colposcopy procedure and possible outcome also contributed to clients' fear and anxiety. A non-attendee reported that the reason

for not attending her colposcopy appointment was partly due to “feeling a bit scared” of the procedure.

A few clients were also concerned about possible pain associated with the procedure and past negative experiences associated with a pelvic examination, as highlighted by an attendee:

The only thing I’m worried about is getting hurt, I hate that because when I did the Pap smear I was bleeding for two days it was very sore ... That’s the one reason why I hate the gynaecologist! Just for that stuff. I’ll rather do anything else but don’t scratch in there I hate that.

In contrast, a few attendees were more positive and viewed the colposcopy as an opportunity to be diagnosed and receive treatment or to be cured, and thus motivated clients to attend.

Personal factors

Personal factors that influenced colposcopy attendance included transport costs, childcare responsibilities and interruption of work schedules. Both clients and providers reported that transport costs were an important barrier affecting colposcopy attendance. Some clients were unable to afford the transport costs and therefore had not attended colposcopy appointments. A few attendees mentioned having borrowed transport money in order to attend their appointment.

A colposcopy provider working at both the tertiary and community colposcopy clinics reported an increased compliance and a reduced default rate at the community colposcopy clinic when the clinic was situated closer to the patient’s residence:

... Having more local centres where the patient could actually go would increase their compliance quite a lot because as I am out in Khayelitsha there are lots of patients who have defaulted the colposcopy clinic, but they easily come to me because there's no issues, not much expense, not much travelling issues and so on, then I have a good rate of patients that have appointments.

With regard to childcare responsibilities, a client reported that she had to find someone to take her child to school in order to attend her follow-up appointment. A non-attendee was also concerned about who would look after her baby if she had to attend her colposcopy appointment. Furthermore, interruption with work schedules and difficulty getting off work were additional barriers reported which influenced colposcopy attendance.

Health system factors

A myriad of health system factors and failures influenced colposcopy attendance. These factors included inadequate feedback of Pap smear results; a disjointed system of colposcopy scheduling; and a lack of resources, including staff shortages. A third of non-attendees reported that they had not been informed of their Pap smear results and colposcopy appointments and therefore had not attended colposcopy. This situation was highlighted by a non-attendee:

They didn't give me results ... they didn't ... If they told me my results and that I'm supposed to come on that 19th [for colposcopy appointment]*..., but they didn't ... I'm not happy because that means they are not serious about my health.*

Providers reported challenges in reaching clients to inform them of results and colposcopy appointments because of invalid contact details. One clinic provider reported success with clients in collecting their results by sending

text message reminders from her mobile phone. Clinics utilised CHWs to trace clients, but, results using this method were mixed, with some clinics reporting success and others difficulties, due to incorrect address details and a lack of human resources.

A few non-attendees only became aware of their abnormal results and a missed colposcopy appointment when contacted by the colposcopy clinic tracing team. This was confirmed by a non-attendee:

No, I didn't know about that [missed appointment]. *I got a call yesterday from someone at Hospital X that I must be there Friday* [new colposcopy appointment] *because I was supposed to be there on the 28th*.

Human resource issues such as staff shortages impacted negatively on colposcopy attendance. Staff shortages resulted in nurses having to allocate time to other duties and departments, thus leaving less time to follow up clients, as indicated by a clinic provider:

Out of the professional nurses there will be one that is on leave, one on a course and there's always sick children to be seen, now we need to take nurses to see them, and one cannot cope……Maybe if you have time you think I can take out the folders for the people I've sent to colposcopy and check who went….But sometimes you never do it because you work till half past four and then never think of going and checking.

Furthermore, staff shortages contributed to long waiting times. A provider reported that spending a few hours in the clinic queue just to collect a folder and then to receive results was not an incentive for clients to return. It was therefore

suggested by a colposcopy provider that patients be called back for results once a week, bypassing the main clinic system of receiving results.

Staff shortages also influenced patients receiving their Pap smear results. A client reported that when she attended her follow-up appointment to receive her Pap smear result, the clinic nurse was on leave and no other provider was available to assist her. Consequently, the client had not received her results and had therefore missed her colposcopy appointment.

Social support

Social support had a positive impact on client colposcopy attendance. Many clients attending colposcopy reported receiving encouragement and support from friends, family, employers, church groups and even health care providers to attend colposcopy. The following was illustrated by an attendee:

My sister is always saying if you go there for the treatment you will be fine, even my boss at work I tell them the result. They say if you go there for operation ... we'll assist you with everything and my church members they come for prayer ... They just keep me company, they pray for me, they talk with me.

Many non-attendees lacked this support either due to a partner with a limited understanding of Pap smears or due to the client not wanting to confide in anyone.

Discussion

Poor colposcopy clinic adherence is a major problem in low- and middle-income developing countries, including South Africa. Poor adherence decreases screening effectiveness, denies other women earlier appointments, decreases the efficiency of health care resources and increases programme costs [22]. This study provides

insights into reasons for poor colposcopy adherence which, if addressed, could lead to early identification and treatment of women with precancerous lesions.

This study confirms findings from previous studies conducted in South Africa that women lack awareness of cervical cancer as a disease [23-25]. Clients were aware of other types of cancers, but very few were acquainted with cervical cancer. This lack of awareness about cervical cancer could be related to silence of the disease. The silence is influenced by cervical cancer not commonly been spoken about in the public, thus very few people have knowledge of the disease; poor provider communication and knowledge about cervical cancer and the asymptomatic nature of precancerous lesions. Wood et al [26] reported in a South African study that among some cultures, women believed that cervical cancer had to be kept a secret because it involved the "underneath parts". The silence relating to cervical cancer could impact on clients seeking follow-up care for an abnormal Pap smear and on the level of support that women receive from community members.

Results from this study are in accordance with previous studies which show that a lack of knowledge of the purpose of a Pap smear contributes to non-attendance at colposcopy [18, 27-29]. A third of non-attendees had not received results directly from their clinic provider. This may have resulted in clients receiving less education about the Pap smear result, cervical cancer and the colposcopy procedure. However, clients should be educated about Pap smears and the importance of returning for results when a Pap smear is performed. A number of non-attendees were asymptomatic and had a Pap smear as part of a routine check, it is not clear whether the importance of a Pap smear was adequately conveyed in routine clinic check-ups. Importantly, Pap smears forming part of routine checks

should be accompanied by client education to ensure that clients understand the risk of cervical cancer and the importance of returning for Pap smear results.

Being asymptomatic has been confirmed in other studies as a factor influencing screening and follow-up care [26, 30]. Not experiencing any symptoms leads to difficulty in accepting the possible presence of disease and could contribute to colposcopy non-attendance. This highlights that providers must place greater emphasis on explaining that even though women are asymptomatic they could still be at risk of cervical cancer and ensure that clients understand the importance of attending colposcopy follow-up care if required. By collaborating with western health care providers, traditional healers could be a valuable asset in encouraging women to attend colposcopy.

In our study, many women presented at the colposcopy clinic due to experiencing symptoms. This illustrates that women are keen to seek medical attention for a perceived physical condition. Being symptomatic could also be more fear provoking and encourage women in seeking a diagnosis. Our findings are similar to that of Wood et al [26], whereby, women predominantly attended cervical screening services due to experiencing physical gynaecological symptoms such as abdominal pain or vaginal discharge and were eager to find out the diagnosis to their problem. Given, that cervical precancer is asymptomatic greater efforts need to be made to make women and communities aware of the asymptomatic nature of precancer.

During the interviews many questions were raised by clients about an abnormal Pap smear and the colposcopy procedure, highlighting clients' unmet need for information. A similar finding was reported in a South African study exploring

women's experiences of being diagnosed with cervical cancer [31]. Women yearned for additional information relating to cervical cancer in order to increase their understanding about the condition. Improved communication between clinic providers and patients can lead to greater client knowledge, which has been associated with an increase in colposcopy compliance [32, 33]. Clients should be encouraged to ask questions during consultations so that individual concerns can be addressed. In addition, client educational materials explaining the importance of Pap smears, cervical cancer and the colposcopy procedure in local languages understandable to clients are required.

The inadequate provider explanation reported by clients may be related to primary care providers' limited knowledge about the importance of Pap smears and management of women with precancerous lesions. This was illustrated previously by Moodley et al [7] in a study conducted in three provinces in South Africa. The lack of provider knowledge could be related to the limited emphasis allocated to cervical screening in the current nursing curriculum, resulting in nurses being ill equipped with knowledge and skills required for cervical screening services [34].

Psychosocial factors such as fear of cancer as a terminal illness and fear of the unknown influenced colposcopy attendance. Women experienced both fear and anxiety with the abnormal Pap smear result and the colposcopy procedure. Although, the majority of non-attendees had not explicitly reported fear as a primary reason for non-attendance, it was a clear concern for many clients. Thus, fear may have been a contributing factor to non-attendance. Other studies have confirmed that a fear of cancer and fear of the unknown had a negative impact on

colposcopy attendance [10, 18, 29, 30]. This illustrates the importance of addressing client fears during patient consultations.

Clients were fearful of cancer, particularly due to a family history of cancer and the association with death. Our findings are in line with other research – that a family history of, and death resulting from, cancer facilitated colposcopy attendance [16, 30].

Previous studies have reported that women do not attend colposcopy appointments due to fear that the procedure would compromise fertility [10, 16, 29]. This issue was not spontaneously raised by clients in our study. Fertility may not have been an issue for women in this study due to the average age of women being 40 and all clients had at least one child.

Transport costs were an important factor influencing colposcopy attendance. Many non-attendees were unemployed and were unable to afford the transport costs to attend their appointment. Availability of colposcopy services mainly at tertiary and secondary hospitals and performed by specialists further restricts client access [35]. The impact of transport and distance has been confirmed in other studies as a barrier to colposcopy attendance [7, 11, 36]. Proximity to health facilities is an important factor in increasing access to health care and for improved health outcomes [37]. This provides an important reason for district based health care [38].

Other South African studies have found that health system factors including inadequate feedback mechanisms and staff shortages have a considerable effect on colposcopy attendance [7, 11, 12]. In our study, inadequate feedback mechanisms

and staff shortages resulted in clients not being informed of their results thus leading to non-attendance at colposcopy.

A variety of methods were used to inform clients of Pap smear results and colposcopy appointments, but there was no co-ordination between methods. A few methods included: a colposcopy letter sent via the postal service from the cytology laboratory; at times, clients received the letter before being informed about their Pap smear results from their clinic provider; a telephone call received from a clinic provider or from the colposcopy clinic tracing team; or with a combination of methods. The lack of standardisation and co-ordination involved in the process of informing clients of Pap smear results and referral to colposcopy appointments point towards the fragmentation of services and contributes to difficulties in providers monitoring which clients have been informed of results and colposcopy appointments. The disjointed system between the laboratory, the primary level clinic, and the colposcopy clinic, leads on the one hand to a duplication in informing clients of results and colposcopy appointments, and on the other hand some clients being missed altogether. This is an inefficient use of financial and human resources. A standardised system of colposcopy scheduling is needed, with the various role players having clearly defined responsibilities to avoid women with abnormal Pap smears from slipping through the system. A uniform, electronic-information system which allows providers from the different facilities to record which clients have been informed of Pap smear results and colposcopy appointments, and which clients have defaulted, is required. This will allow for a coordinated system of monitoring and assist with client tracing.

The introduction of electronic medical records (EMR) may also assist health facilities in keeping track of patients who need to return for follow-up procedures

and improve efficiency. However, this technology may not be feasible for South Africa at present, but should certainly be integrated in the health care system in the near future.

This study had a few limitations. Firstly, some clients were less receptive to communicating via the telephone and could have influenced the depth of their responses. Secondly, even though clients were conversant in English and Afrikaans, neither may have been their first language and could have influenced their understanding and ability to fully express their experiences. Thirdly, the results from this study are not necessarily generalisable to other contexts as the study was conducted predominantly in an urban setting. People living in rural areas could have other barriers. However, results from this study can offer valuable insight into understanding barriers and facilitators that women with abnormal Pap smears may experience.

Recommendations

Interventions to improve knowledge and understanding of Pap smears and cervical cancer are needed at various levels.

1) **At the general public level**

   Mass education programmes to increase community awareness about cervical cancer, the purpose and possible outcomes of Pap smear screening, as well as emphasise the importance of further evaluation of an abnormal Pap smear. Collaborating with traditional healers could assist with increasing community awareness and encourage women to attend colposcopy.

For women having Pap smears

Education should emphasise that precancerous lesions can be asymptomatic and stress the importance of follow-up. Psychosocial factors should also be addressed during the Pap smear consultation to reduce client fears.

At the health system level

Education programmes on Pap smears, cervical cancer and the colposcopy procedure are required at health facilities to ensure that clients are adequately informed.

A standardised system of informing clients of results and colposcopy appointments is essential to ensure clients requiring colposcopy are informed of Pap smear results and appointments. A centralised information system is required to ensure monitoring of clients attending colposcopy and to decrease patient LTFU.

Additional training should be provided to primary level nurses to ensure that a quality service is provided and client concerns addressed.

Colposcopy services should be established closer to the community, for example, at primary health care clinics. Training nurses and general practitioners to perform colposcopies could make the services more accessible.

It would be valuable to fast track clients returning to the clinic for Pap smear results to improve efficiency and encourage clients to collect results. The implementation of EMR could also decrease waiting times and improve efficiency.

Client contact details should be updated at each patient visit so that clients are able to be reached.

Better forms of tracing which are cost effective and efficient are required to reduce LTFU of clients. Since the majority of patients use mobile phones, text messages with short information messages about Pap smears and cervical cancer can be used as reminders to collect Pap smear results and to attend colposcopy appointments. Text messages have been found to be as effective as telephone reminders in increasing adherence to general outpatient appointments, and are more cost effective [40]. It would be worthwhile testing the effectiveness of text messages as a reminder system for colposcopy attendance and as a means of tracing, for future research.

Conclusions

This study identified multiple barriers influencing attendance at colposcopy. The most important barriers included a lack of knowledge of the importance of a Pap smear and the colposcopy procedure; a lack of awareness of cervical cancer as a disease; being asymptomatic; transport costs; and health system failures including the inadequate feedback of Pap smear results and a disjointed system of colposcopy scheduling. Addressing these barriers can improve colposcopy adherence and ultimately decrease cervical cancer morbidity and mortality.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

SD was involved in designing the study, the writing of the proposal, and was responsible for data collection, data analysis, interpretation of data and drafting of the manuscript. JM participated in designing the study, was involved in supervision of the research project and critically revised the proposal and manuscript. JH was involved in supervising and critical revision of the manuscript. All three authors read and approved the final draft.

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PART D: APPENDICES

Addendum 1

Interview Guide for Clients

Good morning,

We will be having an interview to discuss why women do and do not attend their colposcopy follow-up appointments after having an abnormal Pap smear result. We will also be looking at your knowledge and experiences of cervical cancer, Pap smears and colposcopy. I reassure you that all information discussed will be kept confidential.

Exploring clients' knowledge and experiences

Individual factors:

1. Could you tell me why you are here today?
2. How do you feel about today's appointment?
3. Could you tell me what the importance is of having a Pap smear?

3.1. Could you tell me what made you have a Pap smear?

3.2. Could you describe/discuss your experiences thus far since you received your abnormal Pap smear result?

4. Could you tell me what do you know about the procedure or test you coming for today?

4.1. Have you had any difficulties or problems in coming for your appointment today?

Probe if unable to answer - time off from work?
-Problems with childcare?
-Transport?
- Or any other?

5. Many women do not attend their follow–up appointment after an abnormal Pap test. Why do you think this is so?

(If did not attend):

5b. Did you know that you had a colposcopy appointment on (day)?

5b.1 Could you tell me what the reason/s were for not attending?

5b.2. Are you still interested in attending/ making another appointment?

Ask question 3 and 4, then continue

Intrapersonal factors:

6. Have you told anyone about your abnormal smear or that you not feeling well? Who?

If No, how do you feel about being the only one knowing about your abnormal Pap smear?

6.1. Have you received any help or support from them? In what way have they helped or supported you?

If No, would you have liked to receive support from someone? What kind of support or help would you have liked to receive?

Institutional/Health system factors:

7. How did you find out that you needed a colposcopy?

7.1. What did the clinic staff tell you about colposcopy?

7.2. Who explained the result of your Pap smear to you?

7.3. Do you understand what the result means?

- Can you tell me what it means?

8. Do you have any concerns about the procedure? Or about the medical staff ?

9. Can you tell me, the health services you received at the time of having the Pap smear, how can it be improved or made more convenient for you as a patient?

Community/Environmental factors:

10. How do the people in your community (e.g. friends, family, neighbours, leaders) view someone with cervical cancer?

11. Can you tell me if there are any other treatments that you have used for your illness before coming to the doctors for help? e.g. herbal or traditional

Probes - What kind of treatment/s have you received?

- How effective was it?

10. Is there anything else you concerned about or you would like to share?

Probes - Anything regarding the Pap smear?

- The colposcopy procedure?

Well, this brings us to the end of our interview.

Thank you very much for sharing your experiences with me, just to reassure you that all information shared is strictly confidential.

Good luck with your appointment.

Addendum 2

Client Information Form

Study: Barriers and facilitators of colposcopy attendance among women following an abnormal pap smear in Cape Town.

Participant archival number: Date of interview:

Age:

Address:

Interview language:

Contact number: (H) cell:

Nationality:

Marital status: single married divorced widowed

Employment:

Highest education level:

Children:

Date of Pap smear:

Referring clinic:

Pap smear result:

Addendum 3

Interview Guide with Head of Colposcopy Clinic

Good morning, in our interview we will be discussing the effectiveness of the new telephonic tracing system implemented at GSH in improving attendance rates at colposcopy clinic and the sustainability thereof for the rest of the country. We will also be addressing the use of a sms tracing system and its challenges in an attempt to improve attendance rates at colposcopy clinic.

1.) How effective has the new telephonic tracing system that's been implemented at GSH been in improving the attendance rates as well as retaining the women that had missed their colposcopy appointments?

b.) Can this system at GSH be used at public health facilities across the country? And if so how?

c.) What will be required/ what will it take for this system to be put into operation?

d.) Do you think it will be sustainable?

2.) What are your views about the use of sms's for colposcopy appointment reminders and health information messages?

b.) Do you think it's a good idea? And Why?

c.) What would be the challenges?

d.) With the sms's you want clients to be concerned enough to attend, but at the same time not paralysed with fear and not attend.
What do you think the sms message to clients should entail (i.e. the content)?

Is there anything else you would like to add or share with me?

This brings us to the end of our interview; I thank you very much for taking the time out of your busy schedule for this interview and appreciate you sharing your views with me. Thank you

Addendum 4

Interview Guide for Health Care Providers at the Colposcopy Clinic

Good morning, we will be having an interview addressing barriers and facilitators to colposcopy follow-up by women following an abnormal Pap smear result from a provider perspective.
-Reassurance about confidentiality

Individual and community factors:

1. What factors or issues do you think influences woman's adherence to recommended follow- up care following an abnormal Pap smear?

Probes - anything about their personal circumstances or situation?
- Language barriers?
- Anything about getting medical care?
- Anything about the health care providers?
- Cultural influences? Or beliefs?
- Transport?
- Distance?
- Anything regarding scheduling of appointments?

Health system/ Institutional factors:

2. In your opinion, can you describe the significance of non- attendance at colposcopy assessment following an abnormal Pap smear?

2.1 Do you think this problem of non-attendance is related to the availability of services that is available to women?

Probes - What services are available?
- What services are not available that ideally should be?

3. Can you describe the communication channels between the colposcopy clinic and the referral clinics?

4. What happens to the patients who do not attend colposcopy?

Probe- Is there any way to follow them up? If yes proceed to 4.1.

4.1 How successful has this form of tracing been in retaining women who have missed their appointments?

5. How important do you feel it is for patients to attend their follow-up? appointments?
6. What problems or challenges are you as a health care provider faced with in the provision of Pap smear/colposcopy services to these women?

6.1 How do you think services can be improved in order to improve colposcopy attendance rates?

7. Is there anything else that you would like to share?

Our interview has come to an end, Thank you for your time and your valuable contributions.

Addendum 5

Interview Guide for Health Care Providers at Clinics

Good morning, we will be having an interview addressing barriers and facilitators to colposcopy follow-up by women following an abnormal Pap smear result from a provider perspective.
-Reassurance about confidentiality

Individual /intrapersonal factors, community/ environmental factors:

1. 1. What factors or issues do you think influences women's adherence to recommended follow-up care following an abnormal Pap smear?
Probes - anything about their personal circumstances or situation?
- Language barriers?
- Anything about getting medical care?
- Anything about the health care providers
- Cultural influences? Or beliefs?
- Transport?
- Distance?
- Anything regarding scheduling of appointments?

Health system/ Institutional factors:

2. 1 What is the process that follows once women have come to the clinic for their Pap smear?

2.2 What is the process involved in informing clients of their Pap smear results?

2.3 If patients do not return for their result, what measures are in place to track women in order to inform them of their result?
Probe- What about if it is an abnormal result?

3. Can you tell me how are the colposcopy appointments made for clients?

4. 1 Can you describe the communication channels between your clinic/s and the colposcopy clinic?

4.2 Are you informed about patients that do not attend?

4.3 What is done about the clients that do not attend their colposcopy appointment?

5. How do you feel about the process of appointment making for colposcopy?

6. How important do you think it is for patients to attend their colposcopy follow-up?

7. Do you think this problem of non-attendance is related to the type of services that is available to women?

8.1 What problems or challenges are you as a health care provider faced with in the provision of Pap smear services to women?

8.2 How do you think services can be improved in order to improve attendance rates at colposcopy?

Is there anything else you would like to add?

Our interview has come to an end, thank you for your time and I appreciate your valuable contribution.

Addendum 6

Interview Guide for Administration Assistant at Cytology Lab

Good morning,
We will be having an interview exploring your role in the administration and organisation of colposcopy appointments for women who has had an abnormal Pap smear.

Administration Factors:

1. Can you explain to me what your role is at the cytology lab regarding the Pap smears and colposcopy follow-up appointments?

2.1 How do you determine who needs to be booked for a colposcopy?

2.2 What process do you follow to ensure that a booking is made?

2.3 Once a booking has been made, how are these women informed of their appointment?

Health System Factors:

3. What if women are unable to attend the given appointment date? What happens then?

   Probes- What options are available to them?

   - Are they able to reschedule? How?
   - Are they aware of it?
   - When do they then get another appointment?

4.1 How long do women have to wait before getting an appointment?

4.2 Can you tell me what contributed to the long waiting period?

5. What challenges are you faced with?

5.1 How do you think these challenges can be improved?

Is there anything else you would like to share?

The interview has come to an end. Thank you for your time and valuable feedback.

Addendum 7

Data tracking Form for Interviews Archival Log

Interviewee category (attendee/non-attendee/ HP)	Archival Number	Age	Interviewer	Transcriber	Typist	Interview Date	Interview Language

Addendum 8

Consent to participate in Research: Client Consent Form

Good morning, I am Shanaaz Dawood, a researcher studying at the University of Cape Town. We are conducting a study to better understand reasons why women do and do not attend their follow-up appointment at the colposcopy clinic after having an abnormal Pap smear result.

You are now being requested to volunteer to participate in an interview under the guidance of the University of Cape Town. Participating in the study is completely voluntary and you are not forced to partake.

For this study we will need to conduct an Individual interview. During the interview I will ask you a few questions about yourself, followed by questions with regard to your knowledge of Pap smears, cervical cancer and colposcopy, as well as reasons why you think women attend or do not attend their follow-up appointment. Other questions will involve your experiences regarding the health services received. The interview will be conducted in a private room in which no one else except myself will be present. The total interview should take no more than about 45 minutes. Interviews will be recorded with your permission.

Your name and all information discussed during the interview with the researcher will be kept confidential. Your name will not be used in the research. You will be given a number instead so that you are not identified in the research. The information you provide the researcher with as well as all recordings will only be made available to the main researcher, supervisor and co-supervisor who will assist in analysing the information.

Once again you do not have to take part in the study it is completely voluntary and you can withdraw at any stage of the study. If you decide not to partake in the study you will still continue receiving all the treatment you have been receiving. If you participate you do not have to answer any question that you do not want to.

Potential Benefits:

The information you provide us with will assist in improving health services in the future so that more women at risk of cancer attend their colposcopy follow-up appointments. You will be a given a light refreshment for your time.

Potential Risks and Discomforts:

During the interview process certain questions may cause certain negative feelings to arise which may make you feel uncomfortable, if you feel that you do not want to answer those questions please tell the researcher. During the interview you may feel uncertain or have questions regarding the colposcopy assessment, these can be answered by the specialist doctor.

If during the study you feel that you have been in any way or you have any further concerns regarding the study please feel free to contact the main researcher, Mrs Shanaaz Dawood on 021 5315477 or 0823581282 or email shanaaz59@yahoo.com or you may contact the UCT Health Science Human Research Ethics Committee on 021 4066338.

If you have any questions or concerns regarding the study you may ask them now or later. If you do not have any questions and agree to participate we will go ahead with the interview. Before we start I will ask you to sign this form stating that I, the interviewer have read and explained to you your rights as a participant and you agreed to participate in the discussion.

Participation:

The researcher has read the form to me and I understand the process of the study. It has also been explained to me. I am aware that participation is completely voluntary and I can withdraw at any time. I had an opportunity to ask questions and all questions and concerns have been adequately addressed by the researcher.

Participant signature..... Date.....

Hospital.....

Researcher Name.....

Researcher Signature.....

Telephonic consent

Participant name.....…. Date.....

Researcher Name.....

Researcher Signature.....

Addendum 9

Consent to participate in Research: Health Provider Consent Form

Good Morning, I am a researcher studying at the University of Cape Town.

We are conducting this study to better understand the reasons why women do and do not attend their follow-up appointment at colposcopy clinic after having an abnormal Pap smear result. The results of this study will assist in improving health services, to ensure that more women with abnormal Pap smear results attend their follow-up appointments and receive the appropriate care and treatment, in order to decrease the progression to cervical cancer.

You are now being requested to volunteer to participate in an interview under the guidance of the University of Cape Town. Participating in the study is completely voluntary and you are not forced to partake.

Individual interviews will be conducted in a private room in which you will be asked a few questions with regard to barriers and facilitators to colposcopy attendance, from a providers' point of view. The total interview should take no more than about forty minutes. Interviews will be recorded with your permission.

Your name and all information discussed and disclosed during the interview with the researcher will be kept confidential. Your name will not be used in the research. You will be given a number to ensure anonymity. The information you provide the researcher with as well as all recordings will only be made available to the main researcher, supervisor and co-supervisor who will assist in analysing the information.

Once again you do not have to take part in the study it is completely voluntary and you can withdraw at any stage of the study. If you participate you do not have to answer any question that you do not want to.

Potential Benefits:

The information you provide us with will assist in improving health services in the future so that more women at risk of cancer attend their colposcopy follow-up

appointments. Once the research is complete you will be contacted and provided with the results of the study.

Potential Risks and Discomforts:

There are no foreseeable risks for participating. During the interview process, you may feel some discomfort in answering any question, if you feel that you do not want to answer those questions please tell the researcher.

If you feel that during the study you have been harmed in any way or if you have any further concerns regarding the study please feel free to contact the principal researcher, Mrs Shanaaz Dawood on 021 5315477 or cell 0823581282 or email shanaaz59@yahoo.com or you may contact the UCT Health Science Human Research Ethics Committee on 021 4066338.

If you have any questions or concerns regarding the study you may ask them now or later. If you do not have any questions and agree to participate we will go ahead with the interview. Before we start I will ask you to sign this form stating that I, the interviewer have explained to you your rights as a participant and you agreed to participate in the discussion.

Participation:

I have read the letter and understand the process of the study. It has also been explained to me. I am aware that participation is completely voluntary and I can withdraw at any time. I had an opportunity to ask questions and all questions and concerns have been adequately addressed by the researcher.

Health Provider Signature..... Date.....

Hospital.....

Researcher Name.....

Researcher Signature.....

Addendum 10 Ethics Approval Letter

UNIVERSITY OF CAPE TOWN

Health Sciences Faculty
Research Ethics Committee
Room E52-24 Groote Schuur Hospital Old Main Building
Observatory 7925
Telephone [021] 406 6338 • **Facsimile** [021] 406 6411
e-mail: nosi.tsama@uct.ac.za

18 April 2013

HREC REF: 174/2013

Mrs S Dawood
Women's Research Unit
Public Health & Family Medicine
Falmouth Building

Dear Mrs Dawood

PROJECT TITLE: BARRIERS AND FACILITATORS TO COLPOSCOPY FOLLOWING AN ABNORMAL PAP SMEAR. PATIENT AND PROVIDER PERSPECTIVES

Thank you for responding to the issues raised by the Faculty of Health Sciences Human Research Ethics Committee in your letter dated 16th April 2013

It is a pleasure to inform you that the Ethics Committee has **formally approved** the above-mentioned study.

Approval is granted for one year till the 30 April 2014.

Please submit to the HREC a Progress Report Form, using the standardised Annual Report form if the study continues beyond the approval period. Please submit a Standard Closure Form on completion of the study. (Forms can be found on our website: http://www.health.uct.ac.za/research/humanethics/forms/

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the REC. REF in all your correspondence.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, HSF HUMAN ETHICS

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

Ntsama

Addendum 11 Annual Ethics Progress Report

UNIVERSITY OF CAPE TOWN

FACULTY OF HEALTH SCIENCES
Human Research Ethics Committee

FHS016: Annual Progress Report / Renewal

HREC office use only (FWA00001637; IRB00001938) This serves as notification of annual approval, including any documentation described below.			
☑ Approved	Annual progress report	Approved until/next renewal date	30 April 2015
☐ Not approved	See attached comments		
Signature Chairperson of the HREC	pp TJBurgess	Date Signed	24/04/2014

Comments to PI from the HREC

Principal Investigator to complete the following:

1. Protocol information

Date form submitted	23 April 2014		
HREC REF Number	174/2013	Current Ethics Approval was granted until	30 April 2014
Protocol title	Barriers and facilitators to colposcopy following an abnormal Pap smear: Patient and provider perspectives		
Protocol number (if applicable)			
Are there any sub-studies linked to this study?	☐ Yes ☐ X No		
If yes, could you please provide the HREC Ref's for all sub-studies? **Note:** A separate FHS016 must be submitted for each sub-study.			
Principal Investigator	Shanaaz Dawood		
Department / Office Internal Mail Address	shanaazd@yahoo.com (Principal investigator) Jennifer.Moodley@uct.ac.za (Supervisor)		

RESEARCH ETHICS COMMITTEE
2014 -04- 24
HEALTH SCIENCES FACULTY
UNIVERSITY OF CAPE TOWN

1.1 Does this protocol receive US Federal funding?	☐ Yes	☐ X No
1.2 If the study receives US Federal Funding, does the annual report require full committee approval?	☐ Yes	☐ No

(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)

Addendum 12

Instructions for authors BMC Public Health

Research articles

Criteria | Submission process | Preparing main manuscript text | Preparing illustrations and figures |Preparing tables | Preparing additional files | Style and language

Assistance with the process of manuscript preparation and submission is available from BioMed Central customer support team. See 'About this journal' for information about policies and the refereeing process. We also provide a collection of links to useful tools and resources for scientific authors on our page.

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Research articles should report on original primary research, but may report on systematic reviews of published research provided they adhere to the appropriate reporting guidelines which are detailed in our Editorial Policies. Please note that non-commissioned pooled analyses of selected published research will not be considered.

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See below for examples of word processor and graphics file formats that can be accepted for the main manuscript document by the online submission system. Additional files of any type, such as movies, animations, or original data files, can also be submitted as part of the manuscript.

During submission you will be asked to provide a cover letter. Use this to explain why your manuscript should be published in the journal, to elaborate on any issues relating to our editorial policies in the 'About *BMC Public Health*' page, and to declare any potential competing interests. You will be also asked to provide the contact details (including email addresses) of potential peer reviewers for your manuscript. These should be experts in their field, who will be able to provide an objective assessment of the manuscript. Any suggested peer reviewers should not have published with any of the authors of the manuscript within the past five years, should not be current collaborators, and should not be members of the same research institution. Suggested reviewers will be considered alongside potential reviewers recommended by the Editorial team, Editorial Advisors, Section Editors and Associate Editors.

Assistance with the process of manuscript preparation and submission is available from BioMed Central customer support team.
We also provide a collection of links to useful tools and resources for scientific authors on our Useful Tools page.

Preparing main manuscript text

General guidelines of the journal's style and language are given below.
Overview of manuscript sections for Research articles
Manuscripts for Research articles submitted to *BMC Public Health* should be divided into the following sections (in this order):

- Title page
- Abstract
- Keywords
- Background
- Methods
- Results and discussion
- Conclusions
- List of abbreviations used (if any)
- Competing interests
- Authors' contributions
- Authors' information

- Acknowledgements
- Endnotes
- References
- Illustrations and figures (if any)
- Tables and captions
- Preparing additional files

You can download a template (Mac and Windows compatible; Microsoft Word 98/2000) for your article.
For reporting standards please see the information in the About section.

Title page
The title page should:

- provide the title of the article
- list the full names, institutional addresses and email addresses for all authors
- indicate the corresponding author

Please note:

- The title should include the study design, for example "A versus B in the treatment of C: a randomized controlled trial X is a risk factor for Y: a case control study"
- abbreviations within the title should be avoided

Abstract
The Abstract of the manuscript should not exceed 350 words and must be structured into separate sections: **Background,** the context and purpose of the study; **Methods**, how the study was performed and statistical tests used; **Results**, the main findings; **Conclusions**, brief summary and potential implications. Please minimize the use of abbreviations and do not cite references in the abstract. **Trial registration**, if your research article reports the results of a controlled health care intervention, please list your trial registry, along with the unique identifying number (e.g. **Trial registration**: Current Controlled Trials ISRCTN73824458). Please note that there should be no space between the letters and numbers of your trial registration number. We recommend manuscripts that report randomized controlled trials follow the CONSORT extension for abstracts.
Keywords
Three to ten keywords representing the main content of the article.

Background

The Background section should be written in a way that is accessible to researchers without specialist knowledge in that area and must clearly state - and, if helpful, illustrate - the background to the research and its aims. Reports of clinical research should, where appropriate, include a summary of a search of the literature to indicate why this study was necessary and what it aimed to contribute to the field. The section should end with a brief statement of what is being reported in the article.

Methods

The methods section should include the design of the study, the setting, the type of participants or materials involved, a clear description of all interventions and comparisons, and the type of analysis used, including a power calculation if appropriate. Generic drug names should generally be used. When proprietary brands are used in research, include the brand names in parentheses in the Methods section.

For studies involving human participants a statement detailing ethical approval and consent should be included in the methods section. For further details of the journal's editorial policies and ethical guidelines see 'About this journal'.
For further details of the journal's data-release policy, see the policy section in 'About this journal'.

Results and discussion

The Results and discussion may be combined into a single section or presented separately. Results of statistical analysis should include, where appropriate, relative and absolute risks or risk reductions, and confidence intervals. The Results and discussion sections may also be broken into subsections with short, informative headings.

Conclusions

This should state clearly the main conclusions of the research and give a clear explanation of their importance and relevance. Summary illustrations may be included.

List of abbreviations

If abbreviations are used in the text they should be defined in the text at first use, and a list of abbreviations can be provided, which should precede the competing interests and authors' contributions.

Competing interests

A competing interest exists when your interpretation of data or presentation of information may be influenced by your personal or financial relationship with other people or organizations. Authors must disclose any financial competing interests; they should also reveal any non-financial competing interests that may cause them embarrassment were they to become public after the publication of the manuscript.

Authors are required to complete a declaration of competing interests. All competing interests that are declared will be listed at the end of published articles. Where an author gives no competing interests, the listing will read 'The author(s) declare that they have no competing interests'.

When completing your declaration, please consider the following questions:

Financial competing interests

- In the past five years have you received reimbursements, fees, funding, or salary from an organization that may in any way gain or lose financially from the publication of this manuscript, either now or in the future? Is such an organization financing this manuscript (including the article-processing charge)? If so, please specify.
- Do you hold any stocks or shares in an organization that may in any way gain or lose financially from the publication of this manuscript, either now or in the future? If so, please specify.
- Do you hold or are you currently applying for any patents relating to the content of the manuscript? Have you received reimbursements, fees, funding, or salary from an organization that holds or has applied for patents relating to the content of the manuscript? If so, please specify.
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Are there any non-financial competing interests (political, personal, religious, ideological, academic, intellectual, commercial or any other) to declare in relation to this manuscript? If so, please specify.

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In order to give appropriate credit to each author of a paper, the individual contributions of authors to the manuscript should be specified in this section.

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We suggest the following kind of format (please use initials to refer to each author's contribution): AB carried out the molecular genetic studies, participated in the sequence alignment and drafted the manuscript. JY carried out the immunoassays. MT participated in the sequence alignment. ES participated in the design of the study and performed the statistical analysis. FG conceived of the study, and participated in its design and coordination and helped to draft the manuscript. All authors read and approved the final manuscript.

All contributors who do not meet the criteria for authorship should be listed in an acknowledgements section. Examples of those who might be acknowledged include a person who provided purely technical help, writing assistance, or a department chair who provided only general support.

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relevant background information. Please refer to authors using their initials. Note this section should not be used to describe any competing interests.

Acknowledgements

Please acknowledge anyone who contributed towards the article by making substantial contributions to conception, design, acquisition of data, or analysis and interpretation of data, or who was involved in drafting the manuscript or revising it critically for important intellectual content, but who does not meet the criteria for authorship. Please also include the source(s) of funding for each author, and for the manuscript preparation. Authors must describe the role of the funding body, if any, in design, in the collection, analysis, and interpretation of data; in the writing of the manuscript; and in the decision to submit the manuscript for publication. Please also acknowledge anyone who contributed materials essential for the study. If a language editor has made significant revision of the manuscript, we recommend that you acknowledge the editor by name, where possible.

The role of a scientific (medical) writer must be included in the acknowledgements section, including their source(s) of funding. We suggest wording such as 'We thank Jane Doe who provided medical writing services on behalf of XYZ Pharmaceuticals Ltd.'

Authors should obtain permission to acknowledge from all those mentioned in the Acknowledgements section.

Endnotes

Endnotes should be designated within the text using a superscript lowercase letter and all notes (along with their corresponding letter) should be included in the Endnotes section. Please format this section in a paragraph rather than a list.

References

All references, including URLs, must be numbered consecutively, in square brackets, in the order in which they are cited in the text, followed by any in tables or legends. Each reference must have an individual reference number. Please avoid excessive referencing. If automatic numbering systems are used, the reference numbers must be finalized and the bibliography must be fully formatted before submission.

Only articles, datasets, clinical trial registration records and abstracts that have been published or are in press, or are available through public e-print/preprint

servers, may be cited; unpublished abstracts, unpublished data and personal communications should not be included in the reference list, but may be included in the text and referred to as "unpublished observations" or "personal communications" giving the names of the involved researchers. Obtaining permission to quote personal communications and unpublished data from the cited colleagues is the responsibility of the author. Footnotes are not allowed, but endnotes are permitted. Journal abbreviations follow Index Medicus/MEDLINE. Citations in the reference list should include all named authors, up to the first 30 before adding '*et al.*'..

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All web links and URLs, including links to the authors' own websites, should be given a reference number and included in the reference list rather than within the text of the manuscript. They should be provided in full, including both the title of the site and the URL, in the following format: **The Mouse Tumor Biology Database** [http://tumor.informatics.jax.org/mtbwi/index.do]. If an author or group of authors can clearly be associated with a web link, such as for weblogs, then they should be included in the reference.

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Koonin EV, Altschul SF, Bork P: **BRCA1 protein products: functional motifs.** *Nat Genet* 1996,**13:**266-267.

Article within a journal supplement

Orengo CA, Bray JE, Hubbard T, LoConte L, Sillitoe I: **Analysis and**

assessment of ab initio three-dimensional prediction, secondary structure, and contacts prediction. *Proteins* 1999,**43**(Suppl 3):149-170.

In press article

Kharitonov SA, Barnes PJ: **Clinical aspects of exhaled nitric oxide.** *Eur Respir J*, in press.

Published abstract

Zvaifler NJ, Burger JA, Marinova-Mutafchieva L, Taylor P, Maini RN: **Mesenchymal cells, stromal derived factor-1 and rheumatoid arthritis [abstract].** *Arthritis Rheum* 1999, **42:**s250.

Article within conference proceedings

Jones X: **Zeolites and synthetic mechanisms.** In *Proceedings of the First National Conference on Porous Sieves: 27-30 June 1996; Baltimore.* Edited by Smith Y. Stoneham: Butterworth-Heinemann; 1996:16-27.

Book chapter, or article within a book

Schnepf E: **From prey via endosymbiont to plastids: comparative studies in dinoflagellates.** In *Origins of Plastids. Volume 2.* 2nd edition. Edited by Lewin RA. New York: Chapman and Hall; 1993:53-76.

Whole issue of journal

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